WHAT ARE THE LIVED EXPERIENCES OF PARENTS' UNDERSTANDING AND SUPPORTING THEIR CHILD WITH SELECTIVE MUTISM? AN EXPLORATORY STUDY.

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….children with Selective Mutism have got personalities, they are people, they do have feelings. Just because they're sat there quietly, it doesn't mean that they don't want anything, it doesn't mean that they don't want to be spoken to….they still want to be known, got to know….(Laura, pp 4, 2078-2091)

Abstract

Selective Mutism (SM) is a relatively rare phenomenon, typically arising in early childhood. However, the impact can be severe and widespread and without effective intervention, it can persist into adulthood. Despite this, the phenomenon is largely misunderstood, and access to support for children and their families and guidance for school staff and supporting professionals is scarce, delaying assessment and intervention. Research is also limited and largely consists of quantitative studies and clinical case studies, evaluating the impact of interventions, rather than exploring the views of those who have lived the phenomenon.

This research aimed to provide parents with a unique opportunity to share their lived experience of understanding and supporting their child with SM. In particular, their experience of the onset and impact of SM, experience of support, particularly within their child's educational setting, and how they have coped and maintained their own wellbeing. The study adopted a qualitative design with semi-structured interviews. Six parents with a child between 3- and 7-years-old with a diagnosis of SM were interviewed. The researcher adopted a critical realist epistemological stance and used Interpretative Phenomenological Analysis to interpret the data.

Six superordinate themes were identified across the participants: 'Complex Onset', 'Pervasive Impact', 'Available and Helpful Sources of Support', 'Challenges in Accessing Support', 'Parent Taking on the Role of an Advocate', and 'Parental Coping Strategies'. Parents attributed SM to a combination of biological and environmental factors and reported a detrimental impact on various aspects of their child's life and on their own wellbeing. Access to support was inconsistent and dependent on the understanding of school staff and professionals and available resources. The parents appeared resilient, adopting various coping mechanisms. Through active dissemination, these findings have the potential to improve the understanding of SM and the practice of school staff and professionals, including Educational Psychologists.

Key words: Selective Mutism, parents' lived experiences, educational setting, school staff, Educational Psychologists

Declaration

Student Declaration Form

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Sponsoring Establishment:	N/A
Degree for which thesis submitted:	Professional Doctorate in Educational and Child Psychology

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List of Abbreviations

Abbreviation	Term in Full
AEP	Association of Educational Psychologists
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
BPS	British Psychological Society
CAMH	Child and Adolescent Mental Health
CAMHS	Child and Adolescent Mental Health Service
CBT	Cognitive Behavioural Therapy
Covid-19	Coronavirus Disease (identified in 2019)
CYP	Children and Young People
DfE	Department of Education
DfH	Department of Health
DSM	Diagnostic Statistical Manual
EP	Educational Psychologist
EPS	Educational Psychology Service
GP	General Practitioner
HCPC	Health and Care Professions Council
IPA	Interpretative Phenomenological Analysis
LA	Local Authority
NA	Narrative Analysis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PCPs	Primary Care Physicians
PP	Participant

RCT	Randomised Control Trial
SENCo	Special Educational Needs Coordinator
SEND	Special Educational Needs and Disabilities
SLT	Speech and Language Therapist
SM	Selective Mutism
SMiRA	Selective Mutism Information and Research Association
TA	Thematic Analysis
TEP	Trainee Educational Psychologist
UEL	University of East London
UK	United Kingdom
UNCRC	United Nations Convention on the Rights of the Child
USA	United States of America

Chapter 1: Introduction

1.1 Introduction to Chapter 1

This chapter will first introduce the phenomenon of Selective Mutism (SM), including current and historical definitions, the cause and impact of SM, and intervention approaches. The national and local context of the current research, exploring parents' experiences of understanding and supporting their child with SM, and the researcher's position, including their personal and professional experiences of SM and motivation for conducting research in this area, will then be presented. Finally, the chapter will outline the rationale for the current research.

1.2 What is Selective Mutism?

1.2.1 Current Definition

SM is a severe anxiety disorder (National Health Service [NHS], 2019), characterised by the persistent inability to speak in certain situations or with certain people (Muris & Ollendick, 2015) despite age-appropriate language skills (Nowakowski et al., 2009). The onset of SM is typically in early childhood, between the age of 3- and 5-years-old, corresponding with when children usually start nursery or school (Lawrence, 2017). Most commonly, children are able to speak freely within the privacy of their home but struggle to speak in their educational setting (Frederickson & Cline, 2015), although communication patterns differ between children. Some children can speak in front of peers but not staff, whilst others remain completely silent (Johnson & Wintgens, 2015). Some children can also communicate in a non-verbal manner whilst others cannot (Sluckin & Smith, 2014).

SM is relatively rare with an estimated prevalence of 1% of children (American Psychiatric Association [APA], 2013) or 1 in every 140 children (NHS, 2019). It is more prevalent in females than males, with an estimated ratio of 2:1 (Manassis, 2009), and in bilingual children (Muris & Ollendick, 2015).

To receive a formal diagnosis a child must meet the criteria outlined by the APA (2013) in the Diagnostic Statistical Manual Fifth Edition (DSM-5). As summarised in Table 1, the child's difficulty speaking must be consistent and persistent with a duration of at least one month, interfere with their everyday functioning, and not be better explained by a difficulty acquiring the language or a social communication difficulty.

Table 1

Diagnostic Criteria for SM According to the DSM-5 (APA, 2013)

Diagnostic Criteria
Consistent failure to speak in specific social situations, where there is an expectation for speaking, despite speaking in other social situations.
Interferes with educational or occupational achievement or with social communication.
Duration of at least one month and this should not be limited to the first month of school.
Failure to speak cannot be explained by a lack of knowledge of, or discomfort with, the spoken language required in that social situation.
Failure to speak is not better explained by a communication disorder and does not occur exclusively during the period of Autism Spectrum Disorder or schizophrenia or another psychotic disorder.

1.2.2 Historical Definitions and Conceptualisation

SM was first identified in the 19th century and termed 'Aphasia Voluntaria' (Kussmaul, 1877), reflecting an understanding that children and young people (CYP) voluntarily decided not to speak in certain situations. The term 'Elective Mutism' was then introduced (Tramer, 1934), further emphasising that CYP were 'electing' (or choosing) not to speak (Viana et al., 2009). Research that followed concluded that children with SM were 'oppositional' and 'controlling' (Halpern et al., 1971). However, researchers then started to recognise a close correlation between SM and anxiety, leading to the re-conceptualisation of SM as a form of social anxiety (Black & Uhde, 1995;

Anstendig, 1999). The DSM-4 (APA, 1994) then adopted the term 'SM', emphasising the 'specific' nature of SM (that the child struggles to speak in specific situations) whilst challenging the idea that SM is due to defiance (Johnson & Wintgens, 2015). SM was also re-classified as an anxiety disorder in the DSM-5 (APA, 2013).

Such changes in the conceptualisation of SM over time suggests that 'SM' is a socially constructed term, meaning that it is a label that has been produced by society as opposed to being an inherent or inborn trait (Burr, 2015). This is also clear in how the phenomenon is perceived differently across countries and cultures due to differences in social norms. More specifically, whilst westernised (individualist) countries perceive social anxiety as a negative and problematic phenomenon in need of intervention, many non-westernised (collectivist) countries value a quiet and self-effacing style of interaction. As a result, social withdrawal is perceived as an acceptable, non-problematic response (Rapee et al., 2011).

1.2.3 Cause

The prevailing view in the literature is that the phenomenon that has been termed 'SM' is triggered by intense feelings of anxiety in novel social situations, resulting in the activation of the sympathetic nervous system. This includes an automatic 'freeze' response where the child becomes inhibited and silent as a form of self-protection (Wong, 2010).

However, the cause of such anxiety is still debated. Researchers have concluded that it is likely related to a complex interplay of psychological, biological and ecological factors (Viana et al., 2009). Behaviourists suggest that SM is a learned strategy, where the child learns to remain silent to avoid or escape social demands and associated anxiety (Leonard & Topol, 1993; Busse & Downey, 2011). In contrast, systemic theorists argue that SM is a result of how others interact with the child (Cline, 2014). For example, it has been suggested that parents who are anxious themselves may be overprotective, resulting in the child becoming distrustful of others and the world around them (Wong, 2010). The child's anxiety and withdrawal from the social environment then reinforces the

parent's anxiety, resulting in the parent and child becoming enmeshed (fused together) in an anxious state (Melfsen et al., 2006). Research suggests that teachers may also reinforce a child's silence by removing speaking opportunities (Omdal, 2008). Moreover, research has revealed that SM tends to run in families (Schwartz et al., 2006; Chavira et al., 2007), suggesting a possible genetic vulnerability.

1.2.4 Impact

SM can have a detrimental impact on various areas of a child's development, including their educational achievement (Shipon-Blum, 2007), development of self-help skills and independence (Albrigtsen et al., 2016), and ability to make friends (Wong, 2010; Diliberto & Kearney, 2016). It can also have a profound impact on their emotional wellbeing, resulting in depression (Shipon-Blum, 2007), and lead to school refusal (Christon et al., 2012). Furthermore, it can be an extremely challenging time for parents, siblings, and teachers. For example, parents have reported feeling worried, frustrated, and helpless (Albrigsten et al., 2016).

With targeted intervention most CYP are able to overcome SM, although the time that this takes depends on the persistence and duration of the phenomenon (Stone et al., 2002). It can vary from a week to several years (Cohan et al., 2006).

1.2.5 Intervention

Behavioural Therapy and Cognitive Behavioural Therapy (CBT) have the strongest evidence-base in helping CYP to overcome SM and are most frequently used (Cohan et al., 2006; Viana et al., 2009).

A behavioural approach involves three primary techniques based upon the principles of classical and operant conditioning (helping CYP to associate speaking with positive outcomes and encouraging speech through reinforcement). The first technique, stimulus fading (or sliding-in [Johnson & Wintgens, 2016]), involves gradually exposing the child to feared stimuli (the presence

of other people) in a controlled environment (Hung et al., 2012). The child starts by talking to a trusted adult, typically a parent, in a minimally anxiety-provoking situation, for example in a private room. Another adult, typically a teacher, then gradually 'fades' into the conversation and once the child is able to speak to the teacher, the same approach is repeated to introduce additional adults and peers (Johnson & Wintgens, 2016). The second technique, shaping, involves reinforcing successive approximations to speaking behaviour (Oon, 2010), whilst the third technique, systematic desensitisation, involves helping the child to complete a hierarchy of speaking activities, moving from the least to the most anxiety-provoking activity (Busse & Downey, 2011). CBT involves similar behavioural techniques but also entails helping the child to challenge anxiety-provoking thoughts and learn relaxation strategies (Lang et al., 2016).

However, children with the most complex presentations of SM, including children who have experienced SM for several years, may be offered a combination of therapeutic input and medication, typically anti-depressants such as Selective Serotonin Reuptake inhibitors (NHS, 2019).

1.3 National Context

Despite changes in terminology, there is still very little understanding and awareness of SM in society, resulting in a lack of identification and delays in assessment and intervention. Due to a lack of externalising difficulties many children go 'under the radar' of school staff (Lawrence, 2017) and it can be difficult for parents to pick up on their child's anxiety if they speak freely at home (Sharp et al., 2007). Moreover, even when adults, including professionals, recognise the child's difficulty with speaking, they often misinterpret it as shyness that the child will out-grow (Harwood & Bork, 2011). Historically as many as 40% of CYP with suspected SM have not been accurately diagnosed or referred for intervention (Dummit et al., 1997). This is concerning as the longer the duration of SM, the more entrenched and resistant to intervention it becomes (Bergman et al., 2002; Welsh, 2017). Without early effective intervention, SM can also persist into adolescence and

adulthood (Wong, 2010) and have devastating consequences, including unemployment, an inability to live independently, and social isolation (Walker & Tobbell, 2015).

Despite the importance of early recognition and intervention, there is currently a lack of guidance and support available for professionals, schools, and parents. Much of the guidance comes from the only registered SM charity in the United Kingdom (UK), the Selective Mutism Information and Research Association (SMiRA), and although SM care pathways have been commissioned in some Local Authorities (LAs), there is ongoing debate about which professionals should be involved (Johnson et al., 2014). SM is also overlooked by the National Institute for Health and Care Excellence (NICE), with the guideline for professionals supporting CYP with social anxiety (2013) only briefly mentioning that SM should be considered as part of an assessment. In addition, a recent review into the provision for CYP with communication needs revealed insufficient resourcing across the country, particularly for low prevalence, high impact difficulties such as SM (Bercow, 2019).

Such a lack of guidance and support can result in parents, teachers, and professionals feeling lost about how to support CYP with SM (Johnson & Wintgens, 2001). This is particularly concerning for Educational Psychologists (EPs) who are directly linked to schools and are often the first port of call for support (Boyle & Lauchlan, 2009). It is also inconsistent with legislation, including the Special Educational Needs and Disabilities (SEND) Code of Practice (Department of Health [DfH] and Department of Education [DfE], 2015), the Equality Act 2010, and the United Nations Convention on the Rights of the Child (UNCRC, 1989). The SEND Code of Practice (DfH and DfE, 2015) states that all CYP should receive the support that they need to reach their potential and live a fulfilling life, whilst the Equality Act 2010 states that CYP with SEND should be supported to access the same opportunities as their peers. Furthermore, Article 12 and 23 of the UNCRC (1989) states that CYP with disabilities have the right to "live a full and decent life with dignity and, as far as possible, independence" and that "governments must support parents by creating support services for children". A lack of support is further inconsistent with recent government initiatives. This includes the 'transforming CYPs mental health provision' green paper (DfH and DfE, 2017), which highlights

the need for schools to ensure earlier identification of CYPs' mental health needs and implement support within the school setting to reduce the need for more intensive support later on.

Finally, despite a clear need for improvements in the understanding, awareness, and support of SM, research within the field of SM, particularly in the UK, is extremely limited (Forrester & Sutton, 2015) and much of it is outdated (see chapter 2). Most of the research has also been conducted within the medical field by medical professionals without gathering the views of those with first-hand experience of SM, including CYP and their parents (see chapter 2). Without this insight, it is difficult for professionals to know what support is necessary and likely to be most effective for CYP with SM and their families.

1.4 Local Context

The researcher is a Trainee EP (TEP), currently on placement in an Educational Psychology Service (EPS) in a large LA. Through discussions with colleagues and other professionals, including Specialist Teachers and Speech and Language Therapists (SLTs), and exploring the Local Offer, it became apparent that a lack of understanding of SM and support is also a key issue at a local level. Both parent and professional support groups for SM are currently non-existent. A professional SM interest group was previously coordinated by the Specialist Teaching Team, but this dissolved several years ago due to a lack of funding and staffing. EPs, including those that have worked in the service for several years, also reported that they have rarely been asked to support a child with SM and that when they have, the child has often been in secondary school, suggesting a lack of early intervention. In addition, EPs reported that they have received little to no training on SM, indicating a lack of opportunity to become knowledgeable in this area.

A lack of understanding and support further became clear when the researcher was recently asked by a school to support a 10-year-old with suspected SM. The teacher and parents had never heard of 'SM' and although the Special Educational Needs Coordinator (SENCo) had heard of the term, they were unsure about what interventions to implement. The staff also explained that the child

had been struggling to speak since reception and that this was the first time that they had requested support. Fortunately, as a result of independent study, the researcher felt confident in advising on support strategies. The researcher also knew that the local NHS Speech and Language Therapy service had set up a SM care pathway and helped the school to make a referral for further support. However, this was a challenge due to the pathway still evolving and a lack of information about how to access the pathway and how the pathway works. The researcher further felt that without gathering intel from her conversation with the service, neither she or the school would have become aware of the pathway.

1.5 Researcher's Position

This section is written in first-person. I am a white, middle-class, female, 28-year-old TEP completing a placement in a large LA. My interest in SM and conducting research within this area stems from a number of personal and professional values, beliefs, and experiences, including my own experience of SM in early childhood.

I was 4-years-old and had just started school when I first experienced the phenomenon of SM. I spoke with confidence at home but was unable to speak to anybody within the school setting, including my teachers and peers. I vividly recall the intense feeling of anxiety and fear of having to speak. Whenever I was expected to speak, my heart would race and I developed a lump in my throat, making it difficult to swallow. I also recall teachers encouraging me to speak, for example by refusing to give me a sweet unless I said "thank you", and excluding me from activities unless I spoke. This only worsened my anxiety and I continued to struggle to speak for nearly two years. Reflecting on my experience evokes a strong sense of injustice and has undoubtedly contributed to my core values of autonomy, social inclusion, equality, and hearing the voices of vulnerable populations. I firmly believe that all CYP with SM should receive timely assessment and intervention and be helped to access the same opportunities as their peers. I also believe that professionals need to gather the insider

views of those who have been directly affected by SM to fully appreciate the potential implications of the phenomenon and inform necessary provision and practice.

My core values of social justice and hearing the voices of CYP and their parents have further been enhanced by my career. Before training as an EP, I worked as an Assistant Psychologist in various Child and Adolescent Mental Health (CAMH) services, including a Positive Behaviour Support service where I supported CYP with Autism Spectrum Disorder (ASD) to develop their functional communication and independent living skills. In designing intervention programmes, I consistently worked with the child and their parents, accessing their views and giving them the autonomy to make decisions, and witnessed the powerful impact that this had on their engagement and motivation. I have also had similar experiences as a TEP. For example, by empowering a child with SM (referred to in section 1.4) to express his views through writing and drawing and then speaking to his mother, I was able to gain much more insight into the reasons behind the child struggling to speak and what support he was likely to engage with. This then enabled me to identify the most effective intervention strategies.

I further recognise that as EPs, we have a legal responsibility to access the views of CYP and their parents and involve them in all decision making. For example, the SEND CoP (2015) states that CYP and their parents should be "involved in discussions and decisions about their individual support and local provision" (p. 20). I believe that such responsibilities should also apply to my role as a research practitioner. However, my job title, in particular the word 'psychologist', is associated with a position of power which can act as a barrier to CYP and parents sharing their views in an open and honest manner. A vital part of my role as a TEP and research practitioner is to, therefore, recognise and overcome any potential power imbalances. Within the current study, I empowered parents to share their views by using accessible and non-judgmental language and drawing upon the principles of attunement to demonstrate active listening (Kennedy & Landor, 2015).

Finally, I understand that my personal experience of SM could be problematic when conducting research in this area, for example resulting in bias in the questions I ask or in how I

interpret the findings. However, through remaining aware of my assumptions and beliefs and using tools to put these to the side, such as a research diary (discussed further in chapter 3), I am confident that my research will accurately portray the participants' experiences. My personal experience is also likely to be a benefit, helping me to build rapport and to step into the parents' shoes.

1.6 Rationale for Current Research

In light of the national and local context and the researcher's position, the researcher was interested in exploring the lived experiences of parents of CYP with SM, including their understanding of SM and experience of support for their child, particularly within the education system, and how they have maintained their own emotional wellbeing. Initial searches of the literature revealed no published qualitative research that purely focused on the experience of parents of CYP with SM, making this a unique piece of research. The researcher felt that empowering parents to share their views would add to the knowledge base of SM and contribute to positive social change, including an increase in the awareness and understanding of SM by school staff and professionals (including EPs) and more timely assessment and effective support (for both CYP and parents). The researcher hoped that this would lead to more positive outcomes for CYP with SM, promoting their social inclusion and ability to live fulfilling lives.

1.7 Summary

This chapter has introduced the phenomenon of SM, including the meaning, cause, and implications, and intervention approaches. National and local issues, including a lack of understanding, appropriate support, and research, are also discussed along with the researcher's position. The chapter concludes with a rationale behind the current study. The following chapter will review the literature, which will then inform the research questions.

Chapter 2: Literature Review

2.1 Introduction to Chapter 2

This chapter critically examines the previous research regarding parents' experiences of having a child with SM, including their experience of initial identification and assessment, the cause and impact of SM, intervention, and social inclusion within their child's educational setting. The chapter first outlines the scope and process of conducting the literature review and then provides a critical overview of the findings. Psychological theory is then applied to further interpret the findings. Finally, key gaps in the previous research are highlighted to inform the aims and purpose of the current study.

2.2 Systematic Literature Search Process

An initial scoping literature review was conducted in August 2019 to ascertain the volume and breadth of research within the area of SM and to identify gaps for future research (Peters at al., 2015). The PsychINFO database was used with the single search term of 'Selective Mutism'. This revealed gaps in the research in exploring and understanding the phenomenon outside of the medical field, for example within educational settings, and in exploring CYPs', parents', and teachers' views and experiences of the phenomenon. However, the most significant gap was in exploring parents' experiences, resulting in this becoming the focus of the research.

In April 2020, a systematic literature review was conducted to provide a more rigorous, transparent, and comprehensive synthesis of the available research (with a focus on exploring parents' experiences of SM), resulting in more reliable and valid conclusions (Grant & booth, 2009). The literature review aimed to answer the following question:

'What are parents' views of SM?'

2.2.1 Scope of the Literature Search

2.2.1.1 Date Range. Given the importance of systematic reviews including the most up-to-date research (Lefebvre et al., 2019), the researcher initially searched the literature over the last 10 years. However, as this revealed few relevant studies, the researcher expanded the search to cover the last 20 years. This reduced the risk of missing relevant studies. The researcher was, however, aware that this would result in some dated findings and took this into account when critiquing the papers.

2.2.1.2 Peer Review. Only those studies that had been peer reviewed and published were included to ensure that the research was of the highest possible quality, with the most accurate findings (Kelly et al., 2014).

2.2.1.3 Location and Language. The researcher initially planned to only include those studies that had been conducted in the UK due to possible differences in health and educational services and cultural norms outside of the country, which may affect parents' experiences of SM. However, as no relevant UK-based studies were identified, the search was extended to include papers that had been published in English in western countries, including the United States of America (USA), Canada, Australia, and New Zealand, and Europe. This expanded the available research whilst ensuring similarities in cultural norms, although the researcher remained aware that differences may still exist and took this account when critiquing the papers.

2.2.1.4 Research Design. Given the exploratory nature of the study the researcher was primarily interested in qualitative research. However, as very few studies had adopted a qualitative design, the researcher also included quantitative research. Nonetheless, only those studies that revealed informative findings about parents' experiences were included. Studies where parents had simply completed a diagnostic interview were excluded.

2.2.2 Search Strategy

Two systematic searches were conducted, on the 17/04/2020 and 18/04/2020 (and repeated on the 12/03/2021), using the following databases: PsychINFO, Education Resources Information Centre, Child Development and Adolescent Studies, Academic Search Complete, British Education Index, Education Research Complete, and PsychARTICLES. The first search aimed to identify those studies that had specifically focused on parents of CYP with SM, whilst the second search aimed to identify research that had focused more broadly on anxiety (using the term 'anxiety disorders') but had included parents of CYP with SM as part of their sample. This ensured that no relevant research was missed. The keywords used across the searches are presented in Table 2.1.

Table 2.1

Search Terms

Search	Date	Keyword Search (Using 'Advanced' Function)
Search 1	17/04/2020	A. selectiv* mut* OR selective* mut* OR mute OR mutism B. parent* OR guardian* OR caregiver* OR carer* OR mother* OR father* OR famil* C. experience* OR perception* OR perspective* OR attitude* OR view* OR voice* OR belief* OR feelings OR thoughts Combine search A, B, and C
Search 2	18/04/2020	A. anxiety disorder* OR social anxiety OR social phobia B. parent* OR guardian* OR caregiver* OR carer* OR mother* OR father* OR famil* C. experience* OR perception* OR perspective* OR attitude* OR view* OR voice* OR belief* OR feelings OR thoughts Combine search A, B, and C

Once the keywords had been entered into the databases, the parameters discussed in 2.2.1 were applied. The additional parameters of 'subject' (anxiety disorders) and 'age' (2- to 18-years-old) were also applied to the second search due to revealing a much higher number of papers. To ensure a comprehensive search the researcher also hand-searched Google Scholar. The titles and abstracts of the remaining papers were then screened against inclusion and exclusion criteria (outlined in Table 2.2), leaving 34 papers. The researcher then searched the reference lists of these papers, which revealed three further papers. Finally, the researcher scanned the content of these papers and identified 10 relevant papers to review. The systematic search processes are documented in greater detail in Appendix A. A repeat of both searches approximately eleven months later revealed no additional relevant papers.

Table 2.2

Inclusion and Exclusion Criteria for Literature Review

Criteria	Inclusion Criteria	Exclusion Criteria
Date	• Studies completed over the last 20 years	• Studies completed and published prior to 2000
Language	• Available in the English language	• Not available in the English language
Source Type	• Academic journal • Peer reviewed	• A book or electronic resource (for example, a self-help guide) • Not peer reviewed (unpublished)
Accessibility	• Full text available	• Full text unavailable
Location	• Western countries: USA, Canada, Australia, and New Zealand, and Europe	• Non-western countries
Population	• Parents (or legal guardians) • Mothers or fathers	• Relative other than a parent • School staff and other professionals, such as psychologists and psychotherapists (without also including parents)
Age	• Parent (or legal guardian) of a child	• Parent (or legal guardian) of an infant aged between 0- and 1-years-old or a

	aged between 2- and 18-years-old	young person aged 19-years-old and above
Focus	• Focus on Selective Mutism • Focus on parents' experiences of their child's SM/anxiety as opposed to anxiety experienced by parents themselves • Gathers and presents the parents' experiences (or views, perceptions, attitudes, or feelings) of their child's SM	• Focus on 'anxiety disorders' rather than SM specifically • Focus on anxiety or other mental health phenomena experienced by parents themselves • Fail to gather or present the experiences (or views, perceptions, attitudes, or feelings) of parents i.e. parents just completed a diagnostic interview (for example, the Anxiety and Related Disorders Interview Schedule for DSM-IV for Parents [ADIS-IV P] Silverman & Albano, 1996)
Study Type	• Quantitative, qualitative, or mixed methods study	• Literature review

2.3 Previous Research Findings

After presenting the findings from each study in a tabular form (Appendix B), the researcher grouped the studies according to five themes: 'identification and assessment of SM' (n = 1), 'cause and impact of SM' (n = 4), 'interventions' (n = 6), and 'promoting social inclusion' (n = 1). Two studies sat between two themes and have thus been counted twice. The findings from the systematic review are now discussed according to the themes.

2.3.1 Identification and Assessment of SM

Schwartz et al. (2006) aimed to explore parents' perceptions of the role of Primary Care Physicians (PCPs) in the USA (equivalent to General Practitioners [GPs] in the UK) in identifying and diagnosing SM through a structured survey. Twenty-seven parents of 33 children with SM completed the survey.

All parents reported that they had become aware of the child's difficulty with speaking between the age of 2- and 3-years-old and sought support from a PCP, but only 27% of parents rated

the PCP as 'helpful'. It took an average of eleven and a half months for the PCP to recognise their child's difficulty and less than 40% were referred for a formal assessment. This suggests that there is often a lag between parental and clinician recognition of SM, which can result in parents struggling to access assessment services. This may then reduce opportunities for early intervention.

However, these findings must be interpreted cautiously due to a high chance of sampling bias. More specifically, only those parents who had already attended a SM clinic or were already a member of a SM parent support group took part in the study. It is possible that these parents were more knowledgeable of SM or had particularly struggled to access support, leading them to join the support group. This limits how far the findings can be generalised to parents in the wider community. The recognition of SM and assessment processes may also differ between the USA and UK, further limiting the generalisability of the findings.

2.3.2 Cause and Impact of SM

Cunningham et al. (2004) aimed to clarify what factors are associated with the onset of SM, including internalising and externalising difficulties, parenting style, and family functioning, and what impact SM may have on CYP. Fifty-two children with SM and 52 'typically developing' children and their parents and teachers were included in the study. The children completed reading and arithmetic tests whilst their parents and teachers completed various structured questionnaires. Each parent also completed a structured interview.

The data showed that the children with SM were more anxious but less oppositional than the children without SM, suggesting that SM is related to internalising as opposed to externalising difficulties. However, there were no significant differences in parenting strategies, family functioning, or maternal mental health, suggesting that SM is not related to familial characteristics. Moreover, there was no difference in academic performance, but there were differences in social experiences, with children with SM scoring significantly lower on parent and teacher measures of social cooperation and assertiveness. This suggests that whilst SM may have a detrimental impact on

a child's social relationships, it does not necessarily affect their learning. The authors hypothesise that CYP with SM may actually engross themselves into their academic work to avoid social interaction, preventing them from falling behind academically.

However, there are various limitations associated with this study. Firstly, the children with SM had experienced difficulties in speaking for an average of 6 years 9 months and had all attended a clinical support service. The findings may, therefore, represent children with more enduring anxiety, restricting the generalisability of the findings. Moreover, the children completed the academic assessments at home, a setting where children with SM are commonly less anxious (Sluckin & Smith, 2014). With a reduction in anxiety, the children with SM may have performed better than they would have done in school, limiting the internal validity of the finding that SM did not impair the children's learning.

A similar study, where parents of children with and without SM completed questionnaires to measure their child's and their own emotional wellbeing, was conducted by Alyanak et al. (2013). The children with SM scored higher on all measures of internalising but also externalising difficulties. Furthermore, despite no significant differences in parenting style or attitude, some differences were found in parental wellbeing. For example, fathers of children with SM scored significantly higher on anxiety and depression measures, and a positive correlation was identified between the severity of the child's emotional and behavioural difficulties and maternal psychological distress. This suggests that parental mental health could play a role in the onset of SM. However, with no indication of the direction of the relationship between the wellbeing of parents and children, it may be that parents experience emotional distress as a result of their child's difficulty speaking.

Findings from this study further need to be interpreted cautiously as the authors did not control for differences in cognitive ability. For example, three children with SM had a mild learning disability and five were said to have 'borderline mental capacity', whilst none of the controls fell into these categories. Differing experiences between the parents may have, therefore, been influenced by their child's cognitive profile, reducing the internal validity of the findings.

Various case studies have provided further insight into the consequences of SM, including the case of a 15-year-old girl (Ava) who took part in a CBT programme (Christon et al., 2012). Through clinical interviews, Ava's mother reported that SM prevented her daughter from completing everyday tasks, such as ordering at restaurants, and developing her independence. Ava also reportedly often refused to attend school, which interfered with her academic progress. A case study of 14-year-old identical male twins, who had completed an inpatient multi-model intervention programme (Albrigtsen et al., 2016), identified similar implications. For example, during a semi-structured interview, the twins' parents explained that their sons were struggling to express their basic physical needs, such as asking to go to the toilet. The twins also reported physical signs of anxiety, including stomach ache, and that they were unable to complete basic tasks, such as shopping. Moreover, the parents noted that the family home became filled with "worries and blame" (p. 7) and that they felt exhausted and helpless, resulting in them developing unhelpful coping mechanisms, for example answering for their children. These findings suggest that SM has a detrimental impact on CYP and on the wider family.

However, there are limitations associated with both case studies. Firstly, the content of the interviews, including the questions asked, is not made clear. It is, therefore, unknown if the authors were biased in the data that they reported, reducing the credibility and dependability of the findings. In addition, the older age of the children indicates enduring difficulties with speaking, limiting how far the findings can be generalised, especially to parents of younger children.

2.3.3 Interventions

A key purpose of the study conducted by Albrigtsen et al. (2016) was to explore the twins' and their parents' experience of a 5-week inpatient multi-modal intervention, involving various aspects of family therapy, including 'triangulated conversations'. One therapist also acted as a Participant Observer, observing the family's interactions and partaking in interviews with the parents

and another therapist. Advice and training were further provided for school staff and the twins were prescribed anti-anxiety medication.

The theme of 'effective treatment' was prominent throughout the interview. The parents described their time at the family unit as the "turning point" (p. 8) with the twins gradually starting to speak in school. The parents also emphasised how supportive and helpful the therapists were, understanding and validating their concerns, and noted the effectiveness of the medication. For example, explaining that their sons' anxiety reduced and that they spoke outside of the family home once they had started the medication. Furthermore, the parents reported that the benefits of staying at the unit outweighed the burden. This suggests that the parents found the multi-modal approach effective and acceptable.

However, the findings should be interpreted cautiously as the research interview was administered by a therapist who had already worked closely with the family. This highlights the potential for bias, for example in the questions that the therapist asked and their interpretations of the data. A close relationship between the parents and therapist may have also resulted in a social desirability effect, whereby the parents may have tried to 'please' the therapist in their responses. The researchers briefly acknowledge the possibility of bias, but there is no evidence of active reflexivity, reducing the confirmability of the findings. The process of the parents and twins being interviewed together may have also reduced the extent to which the parents could speak openly and honestly, limiting the credibility of the findings.

The remaining studies under this theme (n = 5) evaluated the impact of CBT programmes. This included two Randomised Control Trial (RCT) studies, two case studies, and a grounded theory study.

The first RCT was conducted by Bergman et al. (2013). Twenty-one children with SM were randomly allocated to a CBT group (20 1-hour therapy sessions with an emphasis on graduated exposure and cognitive restructuring) or a 12-week wait list group. To monitor the impact and acceptability of the therapy, parents and teachers completed various structured questionnaires,

including the Client Satisfaction Questionnaire (Hargreaves & Attkisson, 1978), at baseline and weeks 12 and 24, and at a 3-month follow-up. At each time point, the clinicians also administered a behavioural evaluation (including verbal and non-verbal tasks), whilst the teachers administered a language assessment with the children and the parents completed a diagnostic interview.

The children in the CBT group scored lower on parent-rated (but not teacher-rated) measures of social anxiety at week 12 compared to baseline and the wait-list group. They also demonstrated a significant increase in speaking behaviour between baseline and week 24 on parent- and teacher-rated measures and on the language and behavioural evaluations. In addition, 67% of the children in the intervention group no longer met the diagnostic criteria for SM at week 24 compared to 100% of the wait list children ($p = .002$). Finally, all of the parents and teachers appeared highly satisfied with the intervention, reporting a mean satisfaction rating of 3.79 and 3.72 (out of 4), respectively.

These findings suggest that the parents, teachers, and clinicians perceived the intervention as effective in helping children to overcome SM. The teachers perceived a lack of change in the children's anxiety, but the researchers acknowledge that this may be related to the more internalised nature of anxiety which parents may be more in tune with. The data also suggests that the parents and teachers were satisfied with the intervention. However, without any qualitative information, it is unclear what elements of the intervention the stakeholders found most helpful and what effects they noticed. In addition, children only remained in the wait list condition for 12 weeks. This was ethically necessary but may have not allowed enough time to track natural reductions in anxiety. Such issues limit the internal validity of the findings.

The second RCT study was conducted by Cornacchio et al. (2019). This time 29 children with SM were randomly allocated to a 5-day intensive group behavioural intervention programme (five 6-hour sessions delivered over the summer break) or a 4-week wait-list group. The intervention incorporated various CBT techniques, which the parents were also coached in for 2 hours a day. To monitor the outcomes, the parents completed a diagnostic interview and the parents, teachers, and clinicians completed various structured questionnaires at baseline and week 4, and at 8 weeks into

the new school year. At week 4, the parents also completed the Barriers to Treatment Participation Scale (Kazdin et al., 1997) to measure the feasibility of the intervention.

The findings were largely consistent with those gathered by Bergman et al. (2013). For example, significantly greater improvements across parent-reported verbal behaviour and clinician-reported social anxiety were found in those children who had participated in the intervention between baseline and week 4 compared to controls. Furthermore, 46% of the total sample (including those children who were initially in the wait-list condition) no longer met the diagnostic criteria for SM 8 weeks into their new school year. At this point, teachers also rated the children higher on measures of social and academic functioning. Finally, following the intervention, parents reported a mean satisfaction score of 30.46 (out of 36) and a mean barriers score of 50.54 (out of 2020), suggesting that they perceived the programme as effective and feasible.

However, due to a lack of qualitative information, it is again difficult to truly understand what the parents perceived the key mediators of change to be. A further limitation is that 17.2% of the children were also taking anti-anxiety medication. The authors attempted to control for this by ensuring that the children were on the medication for at least 6 weeks prior to the intervention. However, it is possible that the medication may have taken longer than 6 weeks to reach its optimal effect, meaning that it may have still contributed to a reduction in anxiety. This makes it difficult to judge the effectiveness of the behavioural intervention alone, limiting the internal validity of the findings.

Although limited, some qualitative data regarding parents' experience of CBT has been gained through individual case studies. For example, Fisak et al. (2006) conducted a case study with a 10-year-old boy (LM) who had participated in a 24-session manualised CBT programme. As part of the programme, LM's parents met with a separate therapist to discuss strategies for managing LM's anxiety at home. To evaluate the programme, LM's Father attended two assessment interviews and one parent provided an update on LM's behaviour during each session with the therapist. LM's teacher also provided qualitative feedback through conversations with the therapists.

Overall the findings were very positive. By the 15th therapy session, LM's father reported an increase in LM's social behaviour and increasingly cited examples of this behaviour, including how LM had verbally greeted two new adults. By session 21, LM's teacher also explained that LM spoke to her within the classroom at least four to six times per day. Moreover, at the end of the intervention, LM's parents explained that all parents of children with SM would benefit from similar support. However, LM's father also noted various barriers to implementing the CBT techniques at home, including time constraints. This suggests that LM's parents perceived the CBT programme to be effective, but that they struggled to adopt a therapeutic role.

The findings must, however, be interpreted with caution as the information provided by the parents is very limited. A lack of information about the questions that the parents were asked, alongside a lack of formal qualitative data analysis, also brings into question the credibility of the findings. For example, the researchers may have only reported more desirable findings. The risk of researcher bias is further heightened by how the researchers were involved in delivering the intervention and that there is no evidence of reflexivity. This restricts the confirmability of the findings.

A more recent case study, previously addressed under the theme of 'cause and impact of SM', was conducted by Christon et al. (2012) with Ava. Ava engaged in 61 sessions of a modular CBT programme with a clinician on a one-to-one basis, although her mother also joined the first 10 to 15 minutes of each session to discuss strategies.

Through various clinical interviews and standardised questionnaires, both Ava and her mother reported an increase in Ava's speech and independence and a decrease in her anxiety following the intervention. They reported that Ava could speak freely to both relatives and peers. A diagnostic interview also indicated that Ava no longer met the diagnostic criteria for SM. These findings suggest that both Ava and her mother perceived the CBT programme as effective. However, similar to LM's parents, Ava's mother noted challenges to implementing strategies at home, such as caring for Ava's siblings. This indicates that there may be various barriers to parents becoming therapeutic agents.

However, there are numerous limitations of this study. Firstly, it is unclear what data was gathered from which stakeholder. The views of Ava and her mother and the therapist's interpretations are intertwined and few verbatim quotes are provided. This makes it difficult to truly understand the experiences of Ava's mother in terms of the efficacy and feasibility of the intervention, restricting the credibility of the findings. Secondly, the structure and process of the clinical interviews is unclear. For example, the researchers do not state whether Ava and her mother were interviewed together, reducing the replicability of the study.

A more methodologically sound qualitative study that aimed to explore the process of parents becoming therapeutic agents was conducted by Pishva (2017). Pishva (2017) adopted a grounded theory approach to examine the conditions that supported and challenged the ability of 19 mothers, all of whom had completed a 6-session parent CBT group, to adopt a therapeutic role to help manage their child's anxiety. Each mother took part in an individual unstructured interview.

The findings indicated that the mothers went through four phases of change. The first phase was 'recognising the crisis', where they perceived the detrimental impact of their child's anxiety and experienced their child's distress as their own. At this point, the mothers tried to reduce their child's anxiety in any way possible, for example reducing the expectations placed on their child, and developed the role of a 'comforter and protector'. The second phase was 'making links'. At this point, the mothers developed an understanding of the principles underpinning CBT, enabling them to re-appraise their child's anxiety and recognise how their attempts to comfort their child may have maintained their anxiety. The mothers then seemed to adopt a 'learning' role, where they practiced using CBT techniques. However, they noted various challenges to using the techniques, including a discrepancy with their natural maternal instinct to immediately reduce their child's distress. The mothers then moved into the third phase, 'integrating', where they integrated the most effective strategies into their everyday parenting. At this stage, Pishva (2017) believed that the mothers had adopted the role of a 'supporter'. Finally, the mothers moved into the phase of 'sustaining gains'. At this point, they seemed satisfied with their child's progress but concerned about the future, for

example due to school staff struggling to recognise their child's needs and implement the CBT techniques. At this point, the mothers became an 'advocate' for their child.

The phases of change suggest that parents perceive CBT training as effective in reducing their child's anxiety, but that adopting a therapeutic role and then transferring support to the educational setting is a challenging experience. However, it is important to acknowledge that only one mother had a child with a diagnosis of SM. Despite SM being classed as an 'anxiety disorder' (APA, 2013), research has suggested that children with SM may not respond as quickly to CBT as children with other forms of anxiety (Bergman & Keller, 2007). It is, therefore, possible that parents of children with SM experience different successes and challenges in adopting a therapeutic role, limiting the credibility and transferability of the findings.

2.3.4 Social Inclusion

Omdal (2008) aimed to explore the role of socially inclusive practices by school staff in helping children to overcome SM. Five children with a diagnosis of SM were video-observed in their pre-school or school over a 2-week period and their parents and teachers completed an individual semi-structured interview.

The data from the interviews and videos was presented according to themes, the first of which was 'assessment by the kindergarten/school'. This reflected how the parents of four of the children reported that school staff had accessed advice from external services and embedded extra support in the classroom. In contrast, the parents of the fifth child explained that the school had not sought or put any additional support into place due to their child not presenting with learning or behavioural difficulties. This reinforces the idea that children with SM are vulnerable to going 'under the radar' and may consequently miss out on appropriate support.

However, even for those children who were allocated extra support, this support was not always helpful. For example, the support staff of two children readily withdrew the children from group activities, reducing opportunities for verbal interaction. This was thought to reinforce the

children's silence, leading to the theme of 'interactions in the kindergarten/classroom: inadvertent maintenance of mute behaviour'. The parents of the other two children reported much more effective support, leading to the theme of 'interactions in the kindergarten/classroom: overcoming SM'. These parents explained that staff encouraged their child to engage in group activities and maintained high expectations of their ability to talk, promoting their social inclusion. At a one-year follow-up, only these two children had overcome their fear of speaking.

In attempting to explain the discrepancy in how the children were supported, the author noted differences in how the parents and school staff worked together. More specifically, the parents of the children who overcame their fear of speaking explained that they worked in collaboration with school staff, attending regular meetings and agreeing on targets, whereas the other parents reported challenges in working with staff.

These findings suggest that promoting a child's social inclusion is vital in helping them to overcome their fear of speaking and that consistent communication between parents and school facilitates this practice. However, there are various limitations associated with this study. Firstly, the children were videoed for less than 2 hours across a 2-week period, providing a very limited snapshot. Secondly, it is unclear when the children were videoed. Some of the children may have been videoed during more unsettling times, for example during transition periods which can trigger an increase in anxiety for children with SM (Smith & Sluckin, 2014). This may have then affected their speaking behaviour and how staff responded to them, reducing the credibility of the findings. Finally, the small sample size limits the transferability of the findings.

2.4 Theoretical Framework

"Going beyond mere description to explanation" (Thomas, 2017, p. 97) is key to making sense of phenomenon, such as SM, and resolving associated challenges (Robson & McCartan, 2016). In order to search for explanations, one must explore and apply psychological theory (Tudge et al., 2009).

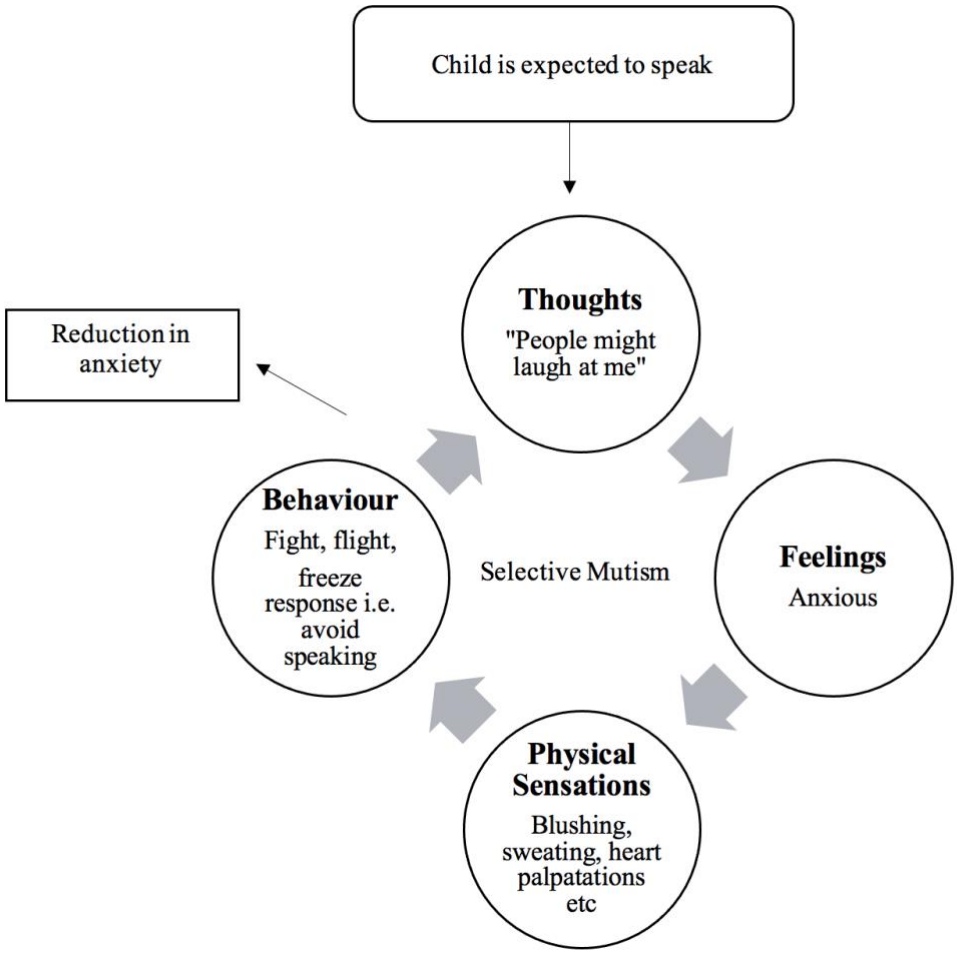
2.4.1 Cognitive Behavioural Theory

Most of the previous studies draw upon behavioural theories, including Beck's (1967) Cognitive Behavioural model, to conceptualise SM. According to Beck's (1967) model, an individual's behaviour is determined by their cognitions (beliefs and thoughts) and feelings and is either 'adaptive' or 'maladaptive'. 'Adaptive' behaviours challenge negative thoughts, whilst 'maladaptive' behaviours offer temporary relief from unpleasant feelings but fail to actually challenge the individual's thoughts. As soon as the individual re-encounters a similar situation, their distress is likely to return, leading to an ongoing cycle of distress.

Consistent with this theory, researchers and professionals, such as Cohan et al. (2006) and Johnson and Wintgens (2015), propose that a child with SM may develop some initial negative thoughts about the consequences of speaking, which then results in anxiety and associated physical sensations, such as muscle tension. These feelings then activate the sympathetic nervous system, resulting in a 'fight, flight, or freeze' response. The child may appear 'frozen' on the spot (and feel physically unable to speak [Holka-Pokorska et al., 2018]) or attempt to escape from or avoid the anxiety-provoking situation. This reduces the child's anxiety in the short term but maintains and reinforces their anxiety and fear of speaking in the long term, resulting in an ongoing cycle of silence and anxiety (Figure 2.1).

Figure 2.1

The Conceptualisation of Selective Mutism within Beck's (1967) Cognitive Behavioural Model



It can be said that Beck's (1967) model is a 'within child' or reductionist approach, focusing on how the child's own thoughts and feelings may lead to the onset of SM and maintain their difficulty speaking. The common use of a reductionist approach may be related to how the majority of studies have been conducted within the medical field by clinicians. However, it is clear from the literature that the environment, including the school system and family system, also plays a key role in shaping a child's emotional wellbeing and whether they are able to overcome SM. Despite these findings, nine of the previous studies make no explicit links to the systems theory.

2.4.2 Systems Theory

The systems theory was first proposed by Bertalanffy (1969) who stated that the "whole is more than the sum of its parts" (p. 19). This suggests that the whole environment, including the family and school context, should be studied in order to understand the development of children and the phenomenon of SM, rather than focusing on individual characteristics. According to this theory, children continuously interact with the environment in a bi-directional manner. The child's behaviour effects and is affected by the behaviour of others (Dowling & Osborne, 2018).

The bioecological systems theory of human development (Bronfenbrenner & Morris, 1998 [Figure 2.2]) effectively demonstrates the complex network of interactions between a child and their environment. According to this framework, the child is at the centre of four interrelated 'layers' of the environment. The first 'layer' is the 'microsystem', the most proximal system to the child. This encompasses direct reciprocal interactions between the child and their immediate environment, including their family, school, and peers. At this 'layer', the child's individual characteristics, including their age and personality, shape how adults and peers respond to them. These responses then shape the child's behaviour (Bronfenbrenner, 1994), for example a teacher who perceives a child to be anxious about speaking may reduce pressures on them to join in with group activities, which may then maintain their silence.

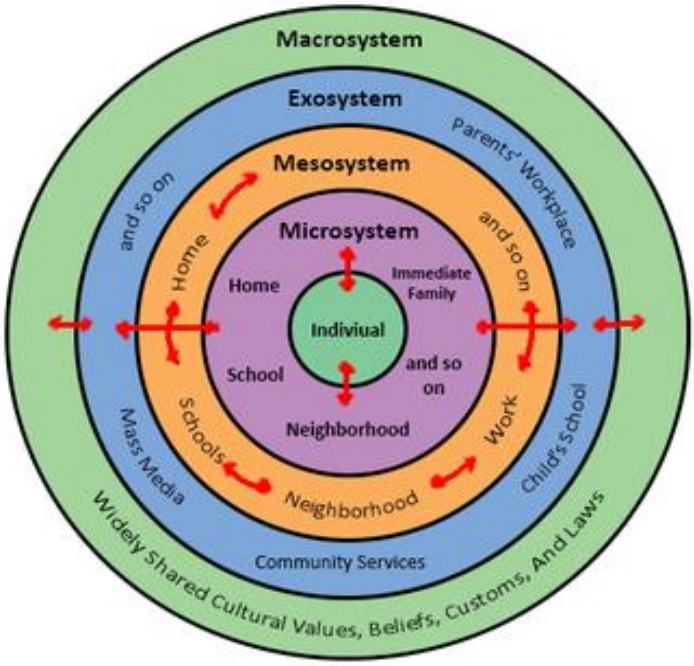
The second 'layer' is the 'mesosystem', representing the interrelations between the child's 'microsystems', including parents and school staff. Interactions between these agents then determine how they respond to the child. For example, when parents and school staff have developed a supportive relationship, they may be more able to engage in joint problem solving and implement more consistent support.

Relationships between parents and school staff also interact with the larger social system, which forms the third 'layer', the 'exosystem'. This includes community support services and professionals who may work with the school and family to enable them to better support the child, such as EPs and SLTs.

The final 'layer' is the 'macrosystem'. This consists of societal and cultural norms, customs, and beliefs, which directly interact with the 'exosystem' and eventually filter down to the individual child (Bronfenbrenner & Morris, 1998). For example, in societies where it is the 'norm' to diagnose and where SM is an accepted diagnostic category, parents may have greater access to assessment and intervention services.

Figure 2.2

The Bioecological Systems Theory (Bronfenbrenner & Morris, 1998)



The bioecological systems theory helps to explain many of the previous findings. In particular, how the perceptions of school staff determined whether they actively promoted the social inclusion of children with SM and how this, alongside how effectively school staff and parents worked together, determined if the children overcame their fear of speaking (Omdal, 2008). The theory also helps to explain the possible interactions between the emotional wellbeing of children and their parents (Alyanak et al., 2013; Albrigsten et al., 2016; Pishva, 2017), and the importance of professionals responding to parental concerns (Schwartz et al., 2006) and working with parents to implement

support (Pishva, 2017). On this basis, the bioecological systems theory (Bronfenbrenner & Morris, 1998) provides a useful framework to understand the phenomenon of SM.

2.4.3 The Transactional Stress and Coping Model

To further understand parents' experiences of SM, including how they adjust and respond, it is useful to draw upon theories of stress and coping, such as the transactional stress and coping model (Lazarus & Folkman, 1984). According to this model, the relationship between a potentially stressful situation and the emotional wellbeing of parents is mediated by each parent's perception of the threat and available coping resources. Parents engage in a complex appraisal process where they first perceive whether their child's experience, such as a difficulty speaking, poses a threat. If a parent perceives a threat, they will then consider the significance of the threat and whether they have the resources to cope, such as access to supportive school staff.

Those parents who perceive a significant level of threat and a lack of coping resources are likely to feel stressed and adopt 'problem-focused' or 'emotion-focused' coping mechanisms. Parents adopting a 'problem-focused' approach will try to actively change the situation, for example by seeking specialist support, whilst those adopting an 'emotion-focused' approach will try to directly reduce any distress associated with the threat, for example by avoiding situations where their child is expected to talk. How effective the parents' response is in 'containing' their child then determines how stressful they perceive the situation to be (Lazarus & Folkman, 1984).

This model is particularly helpful in explaining how parents in the previous studies reported feeling worried and helpless and that they had resorted to using unhelpful coping mechanisms before accessing support from services (Christon et al., 2012; Albrigsten et al., 2016; Pishva, 2017). This again provides a useful framework to understand the phenomenon of SM.

2.4.4 Theory of Psychological Empowerment

To understand the real value of listening to and learning from parents who have directly experienced the phenomenon of SM, it is helpful to consider theories of empowerment. 'Empowerment' is defined as individuals, organisations, and communities gaining authority over personal, social, political, and economic forces to stimulate social change (Rappaport, 2002). Psychological empowerment specifically focuses on the empowerment of individuals (Zimmerman, 1990) and consists of three components: interpersonal, interactional, and behavioural. The interpersonal component refers to an individual's sense of competence and control, whilst the interactional and behavioural components refer to an individual's understanding of the environment and methods to initiate social change and their actions that then stimulate this change (Zimmerman, 1995). This suggests that involving parents in research will develop their sense of self-efficacy and enable them to become active agents in shaping the awareness and understanding of SM in wider society and in improving support. This is evident in the previous literature, for example with the views of parents indicating various necessary improvements to CBT programmes, including a greater emphasis on transferring strategies into schools (Pishva, 2017).

2.5 Linking the Previous Research and Theoretical Framework to the Aims of the Current Research

Based upon the systematic review of the previous literature, it can be said that some research has been conducted into parents' views and experiences of SM but to a very limited extent.

In answering the literature review question, parents often recognise their child's difficulty with speaking at an early age, but then struggle to access clinical recognition and assessment (Schwartz et al., 2006). Parents also tend to associate internalising difficulties with SM (Cunningham et al., 2004; Alyanak et al., 2013) and have experienced detrimental consequences on their child's social, emotional (Cunningham et al., 2004), and physical wellbeing, and academic progress. Some research has also revealed a possible detrimental impact on the emotional wellbeing of the parents

themselves (Christon et al., 2012; Albrigtsen et al., 2016). Moreover, parents perceive multi-modal and more specific interventions, such as CBT, as effective, but may experience challenges in transferring strategies to the home (Fisak et al., 2006; Bergman et al., 2013; Cornacchio et al., 2019) and school context (Pishva, 2017). In becoming a therapeutic agent, parents seem to go through a challenging process where they experience a shift in their natural parenting role (Pishva, 2017). Finally, parents have reported different experiences in terms of how school staff have worked with them to understand and effectively support their child and promote their inclusion (Omdal, 2008).

However, only three of the previous studies solely focused on capturing parental views. The other studies gathered data from various additional stakeholders, including teachers, clinicians, and CYP, and it is often unclear what information was specifically gathered from the parents. Most of the studies also adopted a quantitative design (n = 5) or took a mixed methods approach with an emphasis on quantitative data (n = 2). Parents often completed a structured diagnostic interview alongside a battery of structured questionnaires, leaving little space for their views and experiences to be explored and understood in any detail. In most cases, the researchers made hypothetical links between the questionnaire data without giving parents the opportunity to comment or provide clarity. As a result, the majority of the findings reflect the interpretations of researchers as opposed to the direct experiences of parents, reducing the opportunity for parents to contribute to improvements in practice. In addition, most studies were conducted by researchers within the medical field and little information was gathered about parents' experiences of accessing support within the context of the education system. Implications for educational professionals, such as EPs, are therefore limited. It is also important to note that the researchers were often clinicians who had already worked with the family, suggesting a high risk of bias in their conclusions.

Furthermore, four of the studies were published prior to 2010, resulting in dated findings. The recognition and understanding of SM may have changed over time and affected the parents' experiences, bringing into question the accuracy of the findings. Finally, none of the studies were conducted in the UK. This may indicate various issues, including a lack of awareness and acceptance

of SM or difficulties in accessing a diagnosis within the UK, perhaps due to differences in understanding. For example, with less of an emphasis on understanding SM as a clinical condition requiring clinical input. This may result in very different experiences for parents.

To address the gaps in the literature, the current research aims to explore how SM is uniquely experienced and lived by parents in the UK through adopting an interpretative phenomenological stance. The researcher is particularly interested in how parents have made sense of and responded to such a misunderstood phenomenon and what support they have accessed within the educational system. The research is further unique in that it adopts a systemic lens and applies the Transactional Stress and Coping Model (Lazarus & Folkman, 1984) to interpret and understand the parents' experiences more closely. The findings will also be interpreted through the eyes of a Trainee Child and Educational Psychologist as opposed to a medical professional, providing an additional perspective on the phenomenon of SM. Finally, as the primary purpose of the research is to give parents the opportunity to improve the understanding of SM and practice by health and educational professionals, the research is firmly rooted within the theory of psychological empowerment (Zimmerman, 1990).

2.6 Summary

This chapter has systematically and critically reviewed the previous research regarding parents' experiences of having a child with SM. The findings suggest that whilst parents commonly identify SM when their child is young and experience many detrimental consequences, they may struggle to access assessment and support. Moreover, parents perceive various interventions as effective, but can struggle to adopt the role of a therapeutic agent. Various psychological theories shed further light on the parents' experiences. However, research is extremely limited, with an emphasis on quantitative data collected by clinicians outside of the UK. The current research aims to explore parents' experiences in much greater depth. Chapter three discusses the methodology adopted by the current study.

Chapter 3: Methodology

3.1 Introduction to Chapter 3

Following a review of the previous literature and the rationale for the current study, chapter three will outline the methodology. This includes an overview of the aims and purpose of the study, the research questions, and the researcher's ontological and epistemological positions (critical realism) and understanding of SM. The chapter will then outline the research design (qualitative), recruitment procedure, participant characteristics, and data collection and analysis methods (semi-structured interviews and Interpretative Phenomenological Analysis [IPA]), and the rationale for selecting these methods. Ethical considerations and an exploration of how the researcher promoted the validity and trustworthiness of the data collected will then follow.

3.2 Research Aims and Purpose

3.2.1 Aims

The aim of this research is to address the identified gap in the literature in exploring the lived experiences of parents of children with SM in the UK through qualitative research methods. It aims to empower parents to share their views about what may have led to their child presenting with SM and the impact on their child, themselves, and the wider family. The research also aims to explore parents' experiences of accessing support for their child and the effectiveness of this support, particularly within their child's educational setting, and how they have coped and maintained their own emotional wellbeing. This will hopefully increase the understanding of SM by health and educational professionals, including EPs, and inform their practice. It is hoped that this will result in earlier and more accurate recognition and earlier and more effective support. The overall intention is to, therefore, advocate for the best outcomes for children with SM, helping them to reach their

academic and social potential and "become confident individuals living fulfilling lives" (SEND Code of Practice [DfE and DfH, 2015], p. 92).

3.2.2 Purpose

There are four common purposes of research: exploratory, descriptive, explanatory, and emancipatory (Robson & McCartan, 2016). For real world research where little is known about the phenomenon, an exploratory purpose is usually appropriate (Robson & McCartan, 2011). As already highlighted, there is currently a lack of research focusing on the qualitative experiences of parents of children with SM, and the research that does exist is not detailed enough to capture a deep understanding. The purpose of this study is to, therefore, explore rather than explain or simply describe the parents' experiences.

An emancipatory purpose acknowledges that it is not enough to simply understand the world and that researchers must actively change it by "helping members of an oppressed group take control of their own lives" (Robson & McCartan, 2016, p. 39). Given the aim of the research to provide parents with the opportunity to share their experiences to facilitate positive change for a vulnerable group of children, the research also has an emancipatory purpose. More specifically, it is hoped that the parents will feel heard and valued, giving them the courage to share information that is key to improving the awareness and understanding of SM and support offered by educational settings and professionals, resulting in more positive outcomes. For example, it is hoped that the parents will be able to share information on what support has been most helpful, which professionals can then take into account when providing advice to schools or parents. The use of member checks, where themes from the data are confirmed with the participants, and opportunities to help disseminate the findings will hopefully further empower the parents' contribution to improvements in practice.

3.3 Research Questions

Based upon the aims and purpose of the research, four broad research questions have been formulated:

1. What are parents' experiences of what may have led to their child presenting with SM?
2. What are parents' experiences of the impact of SM?
3. What are parents' experiences of support?
4. What are parents' experiences of coping with their child's SM?

3.4 Ontological, Epistemological, and Axiological Positions

Ontological and epistemological paradigms refer to different assumptions that individuals hold about the social world (Lincoln et al., 2011). Ontology is defined as the nature of reality (Guba & Lincoln, 1994), more simply whether there is an objective reality independent of human interpretations (Richards, 2003). In contrast, epistemology is defined as the nature of knowledge, including what knowledge can be gained and how (Cohen et al., 2007). Moreover, axiology refers to the researcher's values and how these may affect the knowledge gained (Creswell, 2003). Together these assumptions determine how researchers collect (Willig, 2008) and interpret data (Crotty, 1998). It is, therefore, vital that researchers are explicit about their ontological and epistemological positions.

3.4.1 A Spectrum of Research Paradigms

It is helpful to think of ontological and epistemological positioning as a spectrum, with positivism at one end and interpretivism at the other (Sale et al., 2002).

Positivism. Positivist researchers maintain the ontological and epistemological positions of empirical realism and objectivism. This assumes that one true reality exists (Guba & Lincoln, 1994) and that reality can be objectively measured to confirm hypotheses (Sousa, 2010). The axiological beliefs underpinning positivism include an emphasis on 'objective research', ensuring that the

researcher does not interfere with the findings (Cohen et al., 2007). Consistent with these beliefs, quantitative data collection methods are typically used (Sale et al., 2002).

Interpretivism. Interpretivist researchers adopt the ontological and epistemological positions of relativism (Guba, 1990) and subjectivism (Cohen et al., 2007). This assumes that multiple complex realities exist due to individuals construing different meanings (Guba & Lincoln, 1994) and that all knowledge is subjective (Cohen et al., 2007). Researchers must, therefore, interact with the participants and immerse themselves into their world to try to understand their reality (Geertz, 1973). This is underpinned by a value-laden axiological belief, meaning that the researcher's values are likely to affect the findings (Firdaus, 2017). Consistent with these beliefs, qualitative data collection methods are typically used.

Critical Realism. Critical realism sits in between positivism and interpretivism (Pather & Remenyi, 2004), adopting the ontological position of realism and the epistemological positions of subjectivism and constructionism. Critical realists assume that one true reality exists but acknowledge that this reality is complex, underpinned by deep unobservable social structures and causal mechanisms, meaning that reality can only be partially understood (Bhasker, 1975). They recognise that individuals attach their own subjective meaning to events based upon their own experiences (Robson & McCartan, 2016), which then affects their perception of reality (Bunge, 2006). Therefore, researchers must explore the observable reality whilst also trying to uncover unobservable structures and mechanisms to gain a deeper understanding of reality (Bhaskar, 1975). For example, by exploring the insider views of individuals (Geertz, 1973) and interpreting their views to identify social and psychological factors beyond their knowledge (Willig, 2013). Similar to interpretivism, critical realism is also underpinned by a value-laden axiological belief, emphasising the importance of the researcher's beliefs being made explicit (Kwan & Tsang, 2001). This is consistent with qualitative data collection methods.

3.4.2 The Researcher's Epistemological, Ontological, and Axiological Position

A critical realist position is adopted in this research on the basis of the researcher's beliefs and perceptions. The researcher sees SM as a 'real phenomenon', understanding that children may truly struggle to talk as a result of anxiety. This is based upon the researcher's own experience of SM and their work with a child with SM as a TEP (discussed in chapter one). The researcher vividly recalls feeling highly anxious throughout the school day, but particularly during activities where there was an expectation to speak. During these activities the researcher almost felt 'frozen' on the spot and physically unable to speak. A similar state of anxiety was further evident in a 10-year-old child that the researcher worked with during their second year of training. The child also communicated various worries that stopped him from speaking, including a fear of people developing a negative opinion of him. In addition, much research has highlighted various biological implications of anxiety, including an increase in particular hormones, such as cortisol (Weiner, 2019).

However, the researcher also acknowledges that the diagnostic label of 'SM' and the meaning of 'SM' has been socially constructed over time. This seems likely given how the diagnostic label and definition has changed three times since 1877 and the different perceptions of social anxiety between different countries and cultures (as discussed in section 1.2.2). The researcher also understands that the characteristics of SM can differ significantly between children, including in what contexts they struggle to speak, the extent and severity of their difficulty speaking, and how long they experience the difficulty. It is, therefore, likely that individuals will have different experiences and thus form different meanings of SM.

Consistent with a critical realist position, the researcher aims to uncover the structures and causal mechanisms that lead to the onset of SM and what mechanisms are involved in determining the impact of SM, access to support (and the success of this support), and how parents respond and cope. Consistent with these aims, the research will adopt a qualitative design (discussed in section 3.5).

In line with a critical realist position, the researcher will further engage in reflective and reflexive practice throughout the research process. The researcher will remain self-aware of their own experience of SM and the feelings, beliefs, and values that the research may evoke and attempt to put these to the side (Creswell & Creswell, 2018), firstly by keeping a research diary. The researcher will update the diary after each interview and transcription, throughout the data analysis stage, and when interpreting the findings. Secondly, the researcher will discuss their own experiences and feelings during tutorials with their research supervisor. This will allow the researcher to process their feelings and thoughts outside of their interactions with the participants and their data, reducing the risk of biased interpretations.

3.5 Research Design

A quantitative (or fixed) research design is compatible with a positivist paradigm, emphasising the importance of objectively gathering data to gain insight into one true reality (Sale et al., 2002). Quantitative research is experimental in nature, meaning that variables and conditions are controlled and manipulated. There is also a reliance on measuring and quantifying data (Robson & McCartan, 2016). This usually results in highly replicable procedures, meaning that the research can be repeated to confirm the reliability of the findings (Thomas, 2017). However, a fixed design is less appropriate when the researcher wishes to explore phenomenon in detail and capture the "complexities of individual human behaviour" (Robson & McCartan, 2016, p. 103).

A qualitative (or flexible) research design is commonly associated with an interpretivist paradigm, signifying the importance of researchers immersing themselves into the world of the participants (Geertz, 1973). Qualitative research emphasises the importance of gathering deeper information and the most important ideas (Weller et al., 2018) through exploring the views of the participants. A flexible design also anticipates that elements of the study, including the research questions, may change as the research evolves and the most pressing issues are identified.

A critical realism paradigm is compatible with both quantitative and qualitative research (Greene, 2000). However, due to the aim of the study to explore the experiences of parents of children with SM in detail, in order to uncover those mechanisms which may lead to positive change, a qualitative design was adopted. A qualitative research design was also appropriate due the lack of prior research with this population (Donalek & Soldwisch, 2004). It further allowed the researcher to engage in reflexivity (discussed in section 3.4.2) and change elements of the study once they had spoken to the parents. This ensured that the research was most beneficial for the SM community, consistent with an emancipatory purpose.

3.6 Research Participants

3.6.1 Sampling Size and Strategy

Due to the qualitative nature of the research, the researcher recruited just a small number of participants (Creswell & Creswell, 2018). A total of six parents were recruited through a purposive convenience volunteer sampling method. The researcher first invited parents to participate in the research via their contacts with schools within their placement LA, an online parent and professional support group run by the SMiRA charity, and a SLT who runs a parent SM support network. The researcher then liaised with those parents who had responded to the research invitation and selected those parents who fulfilled the inclusion criteria.

3.6.2 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria used to select participants is outlined in Table 3.1. A focus on children within early years and primary school settings was appropriate given that the typical onset of SM is between 3- and 5-years-old (NHS, 2019). The need for a formal diagnosis and current difficulties in speaking also confirmed that SM was one of the child's primary needs, promoting the credibility of the findings. Moreover, it was important that the child was currently attending nursery,

pre-school, or school (or had attended within the last six weeks) due to the research focusing on the parents' experiences of support primarily within the educational setting and the aim of the research to inform educational professionals. Finally, the parents had to be living within the UK due to the researcher's concerns that experiences may differ between countries, for example due to different education and health care systems. However, in light of the low prevalence of SM (NHS, 2019) and the use of a remote data collection method, there were no limits placed on the parents' location within the UK.

Table 3.1

Participant Inclusion and Exclusion Criteria

Criteria	Inclusion Criteria	Exclusion Criteria
Stakeholder	Parent or legal guardian	An extended family member (for example, a grandparent), a member of school staff, or a professional (for example, a SLT)
Location of stakeholder and child	Both the parent and child live within the United Kingdom (any region)	Parent and/or child live outside of the United Kingdom
Child's age	3- to 11-years-old	Under the age of 3-years-old or over the age of 11-years-old
Child's educational setting	Currently attending (or attended within the last six weeks) a nursery, pre-school, or primary school (mainstream or specialist)	Out of education (for more than six weeks)
Child's diagnosis	Formal diagnosis of SM received in the last five years (confirmed by a letter completed by a professional, such as a SLT or Paediatrician)	No formal diagnosis of SM or diagnosis not received within the last five years
Child's SM profile	Currently experiencing difficulties in speaking to staff and/or peers in a nursery, pre-school, or school setting	Not currently experiencing difficulties in speaking to staff and/or peers in a nursery, pre-school, or school setting

3.6.3 Recruitment

Stage One. The researcher created an information and invitation letter (Appendix C) and consent form (Appendix D) and gained ethical approval from the University of East London (UEL [Appendix E]). The researcher then shared the information and invitation letter and consent form with parents through the methods outlined in Table 3.2.

Table 3.2

Methods of Sharing the Information and Invitation Letter

Method Number	Method
One	The researcher emailed the information and invitation letter, alongside the consent letter, to all of the EPs in their placement LA and asked them to share this with the SENCo or headteacher at all of their link primary schools. The EPs were also asked to encourage the SENCo or headteacher to share the paperwork with parents of children attending their setting with a known formal diagnosis of SM.
Two	The researcher gained permission from the trustees of a UK-based charity (SMiRA) to post the information and invitation letter on their parent and professional discussion group on a social media website. The researcher also gained permission to hand out the information and invitation letter at the annual SMiRA conference (attended by parents and professionals) in March 2020, however this was cancelled due to a national lockdown in response to the Covid-19 pandemic.
Three	The researcher emailed a SLT who runs a SM parent support network and asked the SLT to share the invitation letters via email to parents within the network.

Stage Two. The parents directly emailed the researcher to express their interest in taking part in the research. To confirm if the parents met the inclusion criteria, the researcher replied to each email with a list of questions and requested a copy of the letter confirming their child's diagnosis.

Stage Three. The researcher emailed those parents who met the inclusion criteria a consent letter and asked them to read, sign, and return the letter by email. With those parents who did not

meet the inclusion criteria, the researcher sent them a sensitive email explaining that their current circumstances were not consistent with the inclusion criteria. The researcher also thanked the parents for expressing an interest and offered to share the findings of the research on completion. A total of 15 parents who initially expressed interest in taking part in the research did not meet the inclusion criteria, predominantly due to being unable to provide evidence of an official diagnosis of SM. The full recruitment trail, outlining the number of parents who expressed interest in participating in the research and the number of parents who then proceeded to participate, is located in Appendix F.

Stage Four. Once a parent had returned the consent letter, the researcher emailed the parent to arrange a time for the interview.

3.6.4 Participant Characteristics

Demographic information about each parent and their child is detailed in Table 3.3 and Table 3.4.

Table 3.3

Parent Demographic Information

Participant (PP)	Parent's Gender	Parent's Age	Parent's Ethnicity	Parent's Occupation
PP 1 parent	Female	41-years-old	White British	Part time student (previously a Senior Therapy Technical Instructor in a Speech and Language Therapy service)
PP 2 parent	Female	46-years-old	Greek	Medical Doctor
PP 3 parent	Female	36-years-old	White British	Project Manager
PP 4 parent	Female	31-years-old	White British	Full time carer (for older son)
PP 5 parent	Female	45-years-old	White British	Technical Support Specialist (healthcare)
PP 6 parent	Female	39-years-old	White British	Midwife

Table 3.4

Child Demographic Information

Participant (PP)	Child's Gender	Child's Age	Child's Educational Setting	Child's Age at Diagnosis	Child's Ethnicity	Child's Additional Diagnoses	Family Set Up
PP 1 child	Female	4 years 6 months	State pre-school (removed three weeks before the interview)	4-years-old	White British	ASD Pica Sensory processing difficulties	Lives with mother, father, and 6-year-old brother (diagnosis of ASD)
PP 2 child	Male	7 years 7 months	Primary school	5-years-old	Greek	No other diagnoses, but awaiting ASD assessment	Lives with mother, father, and 3-year-old sister
PP 3 child	Female	3 years 5 months	Private nursery	2-years-old	White British	No other diagnoses	Lives with mother, father, and 11-month-old sister
PP 4 child	Female	7 years 4 months	Primary school	7-years-old	White British	No other diagnoses, but awaiting ASD assessment	Lives with mother and 13- and 5-year-old brothers
PP 5 child	Male	7 years 5 months	Primary school	5-years-old	White British	No other diagnoses	Lives with mother, 9-year-old brother, and identical twin brother
PP 6 child	Female	6 years 4 months	Primary school	4-years-old	White British	No other diagnoses	Lives with mother, father, and 3-year-old sister

3.7 Data Collection

Based upon the aim and purpose of the research to explore the parents' experiences in detail, interviews were deemed to be the most appropriate data collection method.

3.7.1 Individual Interviews

The researcher decided to use individual rather than group interviews for numerous reasons. Firstly, group interviews typically focus on the range of the participants experiences ("collective phenomena" [Sim, 1998, p. 351]) and the aim of the research was to explore parents' individual experiences of understanding and supporting their child with SM. As outlined in section 3.2.1, the researcher was interested in the meaning that each parent had made of the cause and impact of their child's difficulty speaking and their individual experience of accessing support for their child and coping mechanisms. The researcher was also keen to gain as much insight into the parents' experiences as possible, which individual interviews would allow to a greater degree, for example by allowing the researcher to follow the lead of each participant and ask probes, prompts, and spontaneous questions related to their individual accounts.

Secondly, the overall purpose of the research was to give parents the opportunity to feel heard and to contribute towards positive change for CYP with SM, promoting their psychological empowerment. Therefore, it was vital that each parent had a 'safe space' where they felt able to express their views. The researcher acknowledged that in a group situation some parents may feel less comfortable, perhaps due to a fear of judgement or conflict of opinion. In light of using an online telecommunication app (Skype), the researcher also acknowledged that there may be differences in computer literacy between the participants, resulting in some parents feeling less confident than others. This could potentially result in some parents giving less information and others dominating the interview, which may then leave some voices unheard, resulting in a limited experience of empowerment. A fear of judgement or conflict could also result in the parents being less honest, resulting in less accurate data, reducing the credibility of the findings.

Thirdly, the researcher was aware of the sensitive nature of the research and how the interview questions may evoke distressing thoughts and emotions, which the parents may not want to discuss in front of others (Willig, 2013). Given the sensitive nature of the research, it was also important that the researcher built up a trusting relationship with each of the participants and promoted confidentiality. This felt more feasible on an individual basis.

Finally, the researcher was mindful of how busy the participants were and how this would make it difficult to find a time when all of the participants were available. Individual interviews were further perceived as feasible due to the small sample size and time available.

3.7.2 Semi-Structured Interviews

According to Thomas (2017), there are three common interview styles: structured, unstructured, and semi-structured.

Structured. Structured interviews consist of pre-determined questions with standardised wording that are asked in a fixed order. These interviews are similar to surveys, but may include more open-ended questions, giving the participants space to explain their answers. These interviews are compatible with fixed research designs (Robson & McCartan, 2016) and are advantageous in that they are quick and simple to administer. However, there is little scope for the researcher to ask follow-up questions, resulting in less detailed information (Thomas, 2017). Using a set list of questions also diminishes the rapport between the participant and the researcher (Mueller & Segal, 2014), which may result in the participant responding in a less honest manner, reducing the credibility of the findings.

Unstructured. Unstructured interviews are less formal. The researcher identifies a general topic but then allows the conversation to develop and the participant to take the lead. Robson and McCartan (2016, p. 293) suggest that this style of interview is more like a "lengthy intimate

conversation". These interviews "greatly aid in establishing rapport" (Miller, 2019, p. 24), provide richer data, and are compatible with flexible research designs. However, they are complex to administer, requiring spontaneous probes, and are, therefore, less appropriate for novice researchers (Robson & McCartan, 2016). Without guiding questions, the participants may also "stray excessively" from the aims of the interview (Segal et al., 2010, p. 19), preventing the researcher from gathering the information that they require to answer their research questions.

Semi-Structured. Semi-structured interviews are described as "the best of both worlds", taking elements from both structured and unstructured interviews (Thomas, 2017, p. 206). The researcher has an interview guide with broad topics and a suggested order and wording for the questions but is able to modify the wording and order of the questions. The researcher can also ask unplanned and follow-up questions to gather further, or clarify, information (Robson & McCartan, 2016). This helps the interview to feel more like a conversation, allowing the participants to discuss what is important to them (Patton, 2002). It also facilitates a deeper understanding of the participants' views whilst also ensuring that the researcher gathers information relevant to their research questions (Kajornboon, 2005). However, there are still some limitations, including difficulties in other researchers replicating the interview, reducing the confirmability of the findings.

Based upon the aims, exploratory purpose, and flexible design of this study, and how the researcher perceived themself to be a 'novice' in conducting research interviews, semi-structured interviews were selected as the most appropriate data collection method.

3.7.3 Design of the Semi-Structured Individual Interview

Prior to the interviews the researcher created an interview schedule (Appendix G). To design the questions, the researcher referred to their four research questions to identify what information they needed to gather and what questions they needed to ask to gain this information. The researcher prioritised a list of questions, which were then peer reviewed by the researcher's supervisor. The final

schedule consisted of 29 questions, 14 of which were demographic questions, requiring a short response. The remaining 15 questions formed the main body of the interview and were open-ended, allowing detailed responses. Each question was also followed by a set of prompts and probes that could be used to encourage the parents to clarify, or provide further, information (Whiting, 2008).

3.8 Procedure

3.8.1 Pilot Study

The researcher considered conducting a pilot study, defined as an investigation to explore the feasibility and success of planned methods before implementing them on a larger scale (Thabane et al., 2010). However, the researcher did not feel that this was necessary due to having a clear idea of the aim and purpose of the current research and how the data would be most effectively gained (through semi-structured interviews as discussed in section 3.7). The researcher also felt that involving parents in a pilot study, alongside the strict inclusion and exclusion criteria that parents needed to fulfil to take part in the final research project (discussed in section 3.6.2), would further limit the number of parents that they could recruit.

3.8.2 Interviews

The researcher initially planned to interview parents on a face-to-face basis whenever possible, as they felt that face-to-face interactions would assist with rapport building. However, based upon the inability of the researcher to claim travel expenses, the researcher limited the distance that they could travel up to 90 miles from their home-town. For one parent within this 90 mile radius, the researcher booked a private meeting room in a children's centre for the interview to take place. For another parent, the researcher liaised with the school of where the parent's child attended to book a

private room. Parents outside of this 90 mile radius were instead offered interviews via video call using Skype.

However, in light of the Covid-19 pandemic and self-isolation measures, all face-to-face interviews were cancelled. Therefore, all of the parents were interviewed over Skype. To continue to ensure an ethical and emotionally-containing approach, the researcher referred to the guidelines to remote working produced by the Association of EPs (AEP [2020]). Consistent with these guidelines, the researcher interviewed the participants from a private room in their home and asked the participants to find a private space in their own home. This ensured that the data was collected in a confidential manner and that the parent felt comfortable to speak honestly. The researcher further gained the parent's consent to record the interview on Skype at the start of each interview. In addition to the information outlined in the AEP guidelines to remote working (2020), the researcher also recognised the importance of still having access to the parents' non-verbal cues, including their body language, to understand how they felt and to recognise when further exploration of an issue was appropriate or inappropriate (Robson & McCartan, 2016). Therefore, the researcher asked the participants to sit in front of the camera on their laptop or phone with their face visible. Moreover, to promote a trusting relationship with the parents, the researcher acknowledged that speaking over Skype felt unusual at the start of each interview and used humour to help the parents to relax. Finally, to ensure that the parents' data was still stored securely, the researcher updated their data management plan (Appendix M). This included the researcher downloading and then immediately deleting the interview recording off Skype following the interview. Each interview lasted between 56 and 105 minutes.

To conduct the interviews, the researcher followed the procedure suggested by Robson and McCartan (2016). The researcher first introduced themself and explained their role and reminded the participant of the aims and purpose of the research, how their data would remain confidential, and their right to withdraw. The researcher then asked the participant if they were happy for their views to be recorded (via the record function on Skype) and if they had any questions before then starting

the recording and interview. To establish rapport, the researcher first asked the parent various warm-up questions, consisting of simple demographic questions. Next, the researcher moved onto the main body of the interview, asking questions about more complex issues. The researcher took a flexible approach, asking the questions included in the interview schedule and additional questions based upon the parent's responses, allowing a natural conversation to flow. The order in which the questions were asked and which prompts and probes were used also varied. At the end of the interview, the researcher asked the parent if they had any other information that they wished to share. Following the interview, the researcher thanked the parent for participating and emailed them a copy of the debrief letter (Appendix H), which included information about anxiety and SM support organisations. The researcher then asked the parent if they had any further questions.

All of the interviews were audio recorded and later transcribed verbatim by the researcher to ensure accurate transcription (Whiting, 2008). The researcher had also initially planned to take handwritten notes during the interviews to support their thinking. However, at the start of the first interview the researcher felt that note taking made it difficult to establish a flowing and comfortable conversation with the participant. Therefore, no further handwritten notes were made. Following each interview, the researcher typed up their reflections into an electronic research diary.

3.8.3 Timeline

The participants were recruited over a 6-month period, between January and June 2020, and the interviews were conducted over a 4-month period, between March and June 2020. To monitor the overall timeline for each stage of the research process, a Gantt chart was created and maintained (Appendix I).

3.9 Data Analysis

When planning the design of the research, the researcher considered various methods of qualitative data analysis and felt that Interpretative Phenomenological Analysis (IPA) was the most appropriate form of analysis for numerous reasons (discussed in section 3.9.3).

3.9.1 Thematic Analysis

Thematic Analysis (TA) is a widely used method that involves identifying themes across data through six simple steps (Braun & Clarke, 2006). As TA is not based upon a pre-existing theoretical framework, it was compatible with the researcher's ontological and epistemological positions. However, TA has "limited interpretive power beyond mere description" (Braun & Clarke, 2006, p. 27), which the researcher perceived as a barrier to answering the research questions and fulfilling the aim of the study to gain an in-depth insight into parents' experiences of SM.

3.9.2 Narrative Analysis

Narrative Analysis (NA) is informed by the theory underpinning narrative therapy, suggesting that individuals use stories to make sense of their experiences. There are various methods of NA, including a life-story method, where the researcher explores how participants talk about their experiences and then translates their experiences into a story (Reissman, 1993). The researcher acknowledged that this could be an empowering approach but was also aware of the limitations, including the limited range of experiences participant narratives capture, making it difficult to create a coherent story (McAlpine, 2016). The researcher was also concerned that their focus on parents of children who had been diagnosed with SM in the last five years and who were still struggling to communicate would limit the extent of the parents' stories. The researcher felt that a narrative approach would have been more appropriate if the aim of the research was to explore parents' experiences across time, for example between the point of their child receiving a diagnosis and the point of their child overcoming SM.

3.9.3 IPA

IPA is committed to exploring how individuals "make sense of their major life experiences" (Smith et al., 2009). It is similar to TA in that it seeks to identify patterns and themes across data, however it is theoretically bound to the theory of phenomenology, hermeneutics, and idiography (Smith et al., 2009). This allowed the researcher to zone in on each of the parent's lived experiences, capturing that deeper meaning and understanding of SM that is currently missing from the literature.

Phenomenology is the "study of experience" (Smith et al., 2009, p. 11). Phenomenologists are concerned with understanding what it is like to be human and how humans construct meaning, going beyond a 'taken-for-granted' way of living (Husserl, 1927). IPA is phenomenological as it focuses on exploring the subjective experiences of individuals (Smith & Osborn, 2008) and attempts to uncover hidden meanings behind how individuals perceive reality (Robson & McCartan, 2016). This means that researchers must put themselves into the shoes of the participants as much as possible (Creswell, 2003).

Hermeneutics is the theory of interpretation. According to this theory, an individual must comprehend the thoughts and language of another individual before they can understand their message (Freeman, 2008). IPA is consistent with this theory through suggesting that research consists of a 'double hermeneutic' process, whereby the researcher attempts to interpret the experiences of participants who are themselves trying to make sense of their experiences. This means that the researcher's interpretations are 'second order' (Smith et al., 2009).

Idiography is concerned with the 'particular' and "grasping the meaning of something for a given person" (Smith et al., 2009, p. 29). IPA focuses on the 'particular' in two ways. Firstly, it explores the experience of individuals in great depth as opposed to understanding experiences and making claims at a whole-group level. Secondly, it focuses on a how one particular phenomenon has been experienced by particular individuals in particular situations. IPA is, therefore, suitable for single case studies and for studies with a small number of participants. To use IPA, the participants

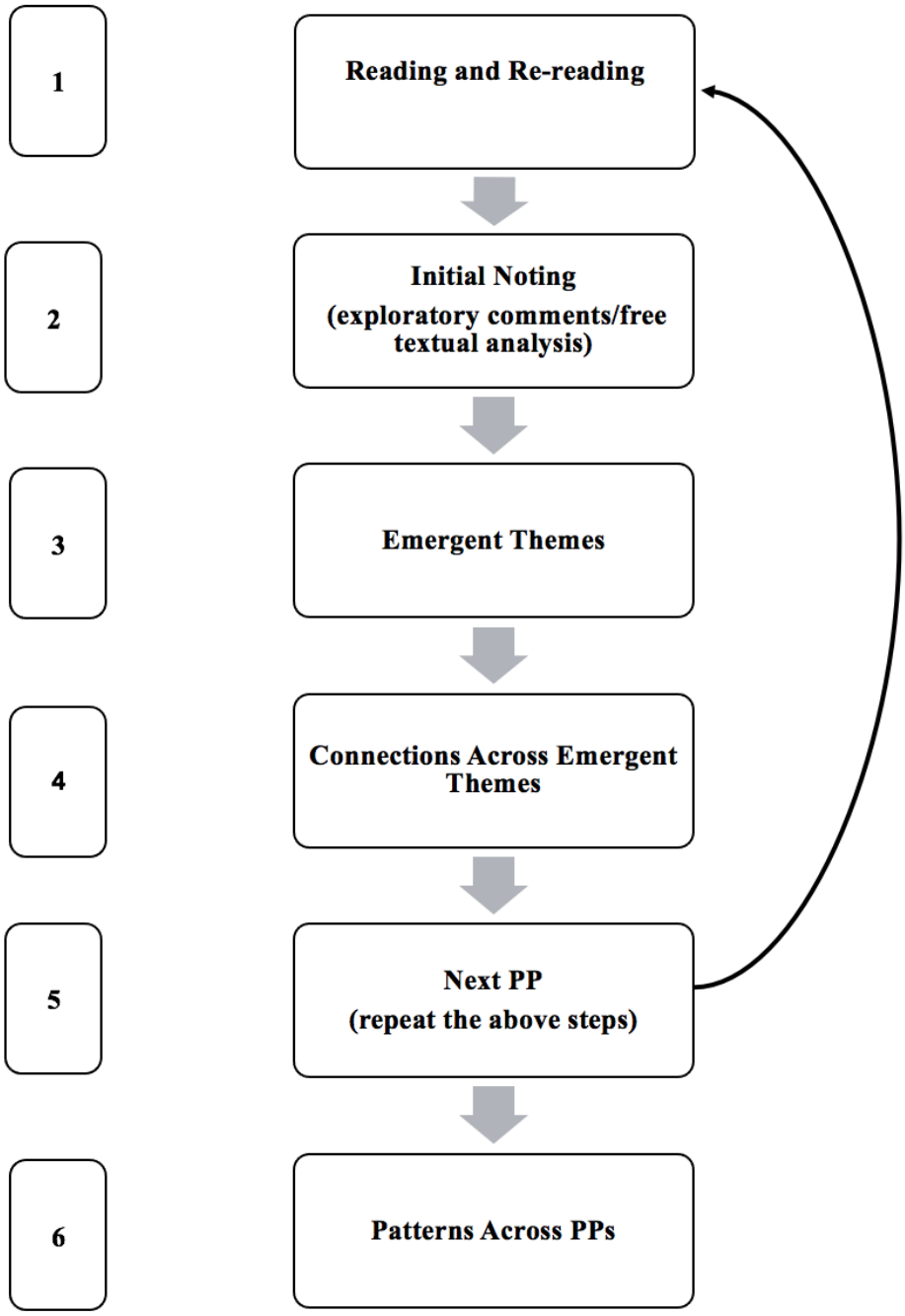
must have also been carefully selected (Smith et al., 2009), for example through tight inclusion and exclusion criteria.

With a focus on understanding human experience, IPA was deemed to be the most appropriate data analysis method for this research. IPA was consistent with the researcher's aim to explore the lived experience of parents of children with SM and the meaning that they have made across four key areas. This ranged from the parents' understanding of the cause and impact of SM to their understanding of available support and what support has been most helpful, and how they have coped with the phenomenon. The theory of hermeneutics was also consistent with the researcher's critical realist epistemological position, emphasising the need to interpret data to uncover hidden structures and mechanisms that determine an individual's experience. Finally, the carefully selected small sample size meant that it was possible to engage in a deeper form of analysis.

IPA Procedure. There is no single prescribed method for conducting IPA. IPA is instead characterised by a set of processes, involving "moving from the particular to the shared and from the descriptive to the interpretative" (Smith et al., 2009, p. 79). IPA is also characterised by a flexible set of principles, including a commitment to understanding the individual experience of the participant and the meaning that they have made (Reid et al., 2005). Furthermore, IPA takes an iterative and inductive approach. This means that the researcher must initially allow themes to emerge from the data and repeatedly re-visit each stage of the analysis (Smith, 2007). Smith et al. (2009) acknowledge that following such complex processes and principles can be very challenging and, as a result, have created a framework with six steps of analysis (Figure 3.1), which the researcher followed. In light of the idiographic theoretical underpinning of IPA, the researcher followed steps one to four with each individual transcript. Step five involved moving onto the next transcript, whilst step six involved bringing the data from all of the participants together to look for commonalities.

Figure 3.1

The Six Steps of IPA



Step One: Reading and Re-reading. The researcher immersed themself into the data through reading and re-reading the participant's transcript multiple times. On the recommendation of Smith et al. (2009), the researcher also read the transcript whilst listening to the audio recording at least once. This ensured that the researcher could imagine the voice of the participant and keep them at the

heart of the analysis throughout the data analysis process. At this stage, the researcher also actively engaged with their research diary, noting down feelings and thoughts that the transcripts evoked. This helped the researcher to 'offload' and 'bracket' (put to one side [Hurrserl, 1927]) their views so that they could fully focus on the participant's individual experiences.

Step Two: Initial Noting (Exploratory Commentary). The researcher's role was to now produce detailed commentary on the data within the transcript, examining one line of text at a time. On the suggestion of Smith et al. (2009), the researcher made three types of comments: descriptive comments, linguistic comments, and conceptual comments (Table 3.5). This ensured that the researcher commented on the participant's views but also on why and how they may have developed those views, gradually moving towards a more interpretative understanding. To assist this process, the researcher copied and pasted the transcript into a table with a column on either side. The researcher used the column on the right-hand side to record their exploratory comments. Each type of comment was also formatted slightly differently, as detailed in Table 3.5. Part of two transcripts with exploratory commentary are located in Appendix J.

Table 3.5

Types of Exploratory Commentary

Commentary Style	Purpose	Characteristics	Formatting
Descriptive	To understand the content of what the participant had said	Noting key words, phrases, and explanations and key events and experiences	Blue text
Linguistic	To explore the language used by the participant and what this might have meant	Noting the use of metaphors, the tone and degree of fluency, pauses, laughter, and repetition	Red italic text
Conceptual	To interpret the participant's understanding of their experiences	Asking curious questions and making hypotheses based upon professional and personal knowledge and	Green text underlined

(going beyond explicit claims)	experience of SM and understanding of psychological theories

Step Three: Developing Emergent Themes. During this step, the researcher primarily focused on the comments that they had made at step two to reduce the volume of the data. The researcher read and re-read their exploratory comments and then created themes based upon comments that seemed similar or connected. The purpose of these themes was to bring together the participant's and the researcher's understanding of the participant's experiences, reflecting what the participant had said and the exploratory comments made by the researcher. The researcher took an inductive approach, allowing all identifiable themes to emerge, even those that did not seem relevant to the research questions and theoretical framework underpinning the research. This ensured that no themes were missed. These comments were recorded next to the transcript (in the left-hand column). Part of two transcripts with identified emergent themes are located in Appendix J.

Step Four: Searching for Connections Between Emergent Themes. The purpose of this step was to look for connections between emergent themes and then group themes together into higher level (superordinate) themes. The researcher first listed all of the emergent themes in a Microsoft Word document and then printed, cut out, and laid the individual themes onto a table. Next, the researcher moved the themes around to group similar themes together, creating 'clusters' and gave each 'cluster' a name (superordinate thematic title). Each superordinate theme was written on a coloured piece of paper above the subordinate themes, resulting in a thematic map. This process took several attempts, and the researcher drew upon various strategies as suggested by Smith et al. (2009). Firstly, the researcher engaged in abstraction, looking for similarities between the themes and grouping similar themes together. Secondly, the researcher engaged in subsumption, transforming related emergent themes into superordinate themes. Thirdly, the researcher engaged in contextualisation, identifying superordinate themes based upon key life events and time. Fourthly,

the researcher engaged in numeration, exploring the frequency in which emergent themes occurred and removing those themes which only occurred once or twice and, therefore, seemed less important to the participant. Finally, the researcher identified how some emergent themes fulfilled a certain function for the participant. The function then became the superordinate theme.

Throughout this step the researcher took more of deductive approach, identifying themes on the basis of the psychological theories underpinning the study, such as the bioecological systems theory (Bronfenbrenner & Morris, 1998), and disregarding themes that did not help to answer the research questions. The process of grouping emergent themes and identifying superordinate themes for participant one and participant three is presented in Appendix K as an example (the themes have been typed out for clarity).

Following the identification of superordinate and subordinate themes (and the creation of a thematic map), the researcher presented the themes in a table and noted the page and line number of where within the transcripts each theme had been pulled from. A few key words from the participant were also recorded next to the theme. This allowed the researcher to keep track of the source of the identified themes. The table of superordinate and subordinate themes for participant one is located in Appendix L as an example.

Step Five: Moving onto the Next Case. The researcher moved onto the next transcript and repeated steps one to four outlined above. The researcher then moved onto the third transcript and so on, until they had analysed all six transcripts. To promote an idiographic approach and allow new themes to emerge from each new transcript, the researcher took a break between looking at each transcript. The researcher also ensured that all annotated transcripts were out of sight. This 'bracketing' process helped the researcher to treat each participant as an individual with the potential to unveil new themes.

Step Six: Looking for Patterns Across Cases. The final step involved examining the themes identified for the participants as a whole group and looking for connections between the themes to form master themes (overarching superordinate themes). The researcher did this through printing the superordinate and subordinate themes for each participant onto coloured paper. Each participant was assigned a different colour to ensure that the participants' views were represented equally. The researcher then cut and laid out the themes on a table and moved the themes around several times to form clusters of identical and similar themes. Each cluster was then assigned a title (superordinate theme). Some of the subordinate themes were also relabelled to reflect the shared lived experiences. The researcher then identified which themes represented the views of three or more (at least 50%) of the participants and excluded the rest for validity purposes. Finally, the researcher created a table in a Microsoft Word document to record the master and emergent themes and then referred back to the original transcripts (as recommended by Smith et al. [2009]) to back up each of the emergent themes with verbatim quotes from the participants. This ensured that the themes accurately represented the participants experiences.

3.10 Ethical Considerations

Formal ethical approval from the UEL was gained in February 2020 (Appendix E).

Throughout the research process, the researcher followed the Health and Care Professions Council (HCPC) Standards of Conduct, Performance, and Ethics (2016) and the British Psychological Society (BPS) Code of Ethics and Conduct (2018), underpinned by four core ethical principles: respect, competence, responsibility, and integrity. The principle of respect is defined as "recognising the inherent worth of all human beings" (p. 5), whilst the principle of competence emphasises the ability of EPs to work within the "recognised limits of their knowledge, skill, training, education and experience" (p. 6). Moreover, the code defines the principle of responsibility as the "responsible use of skills and knowledge" and the "avoidance of harm" (p. 7) and the principle of integrity as being "honest" and "objective" (p. 6). Four moral principles that are also thought to guide ethical practice

were also kept in mind: autonomy (freedom to make choices), beneficence (doing good), non-maleficence (inflicting no harm), and social justice (equal treatment [Beauchamp & Childress, 2009]). This allowed the researcher to prioritise the emotional wellbeing and safety of the participants above everything else.

3.10.1 Informed Consent

The participants were first sent an invitation letter, containing information about the purpose of the research, what their involvement would consist of, and what data would be collected. This letter was written in an accessible manner with minimal jargon to support the participants' understanding. This ensured that the participants were fully informed and could make a valid decision about whether to take part in the research. This was consistent with the principles of integrity and autonomy and standard 2.3 of the HCPC Standards of Conduct, Performance, and Ethics (2019), which is "giving individuals the information that they want or need in a way that they can understand" (p. 6).

Once the participants had volunteered to take part and had confirmed that they met the inclusion criteria, they were sent a consent form to read and sign. Only once the participants had signed and returned this letter were interviews arranged. On the day of the interview the researcher again reminded the participants about the purpose of the research and provided an opportunity for them to ask questions. Consistent with the principles of respect and autonomy, additional verbal consent to continue with the interview was then gained.

3.10.2 Anonymity and Confidentiality

Through the invitation, consent, and debrief letters, the participants were made aware that their data would be pseudo anonymised. This meant that the researcher could trace their data back to their name and remove their data if the participant requested for their data to be withdrawn (although this was only possible up until the point of analysis [see section 3.10.3]). The participants were also

made aware that any identifiable data, including their name and their child's name, the name of the child's school, and information about where they lived, would be anonymised before it was shared with anyone else. In addition, the participants were made aware of when confidentiality may be breached, for example in light of safeguarding concerns. This was consistent with the principles of respect and integrity and standards 5.1 and 5.2 of the HCPC Standards of Conduct, Performance, and Ethics (2019), highlighting the need to "treat information about service users as confidential" (p. 7) and only disclose confidential information in exceptional circumstances.

3.10.3 Right to Withdraw

The participants were made aware of their right to withdraw from the research at any point without explanation or disadvantage. They were also informed that they could request for any of their data to be destroyed at any point but that this request would be only be fulfilled if their data had not reached the point of analysis. This information was highlighted in the invitation, consent, and debrief letters. This was consistent with the principles of respect and autonomy and standard 9 of the HCPC Standards of Performance, Ethics, and Conduct (2019), which is to be "trustworthy and honest" (p. 9).

3.10.4 Data Protection

The researcher followed a data management plan (Appendix M) to ensure that all data was handled and stored in line with the Data Protection Act (The Stationery Office, 2018). This plan was reviewed and approved by UEL in February 2020 and updated in March 2020. Consistent with this plan, the researcher stored data within password protected documents and stored files on various secure systems, including an encrypted external hard drive. In terms of preservation, signed consent letters were destroyed once the researcher had passed their thesis. The rest of the data will be preserved for a maximum of five years to allow time for publication and dissemination.

3.10.5 Protection of the Participants

The researcher identified a medium risk of the participants becoming emotionally distressed due to the sensitive nature of the research. To mitigate this risk (and promote beneficence and non-maleficence), the researcher took a number of steps.

Firstly, the researcher took an empathetic approach and drew upon the principles of attunement (Kennedy & Landor, 2015) to promote an 'emotionally containing' space. For example, the researcher allowed the participants to speak without interruption and actively received their comments and feelings through non-verbal gestures, such as nodding, and repeating back what they had said. The researcher also validated the participants' feelings, experiences, and behaviours, which is key to demonstrating empathy and building therapeutic relationships (Johnston et al., 1998). For example, by using phrases such as "I can understand why you felt that way".

In addition, the researcher explained to the participants that they could skip questions and take a break or discontinue the interview at any point. The researcher also used their professional judgement to recognise when a participant may be showing signs of distress and need a break.

Furthermore, as part of the debrief process, the researcher provided the participants with a list of organisations which they could access for advice and support and a list of key texts that may help them to support their child. This was consistent with principle 2 of the BPS Code of Ethics and Conduct (2018) and standard 3 of the HCPC Standards of Performance, Ethics, and Conduct (2019), highlighting the importance of psychologists working within the limits of their competence.

Finally, the researcher attempted to overcome the potential power imbalance between themself and the participants by using accessible language and arranging member checks with the participants following the interviews to confirm that the data accurately reflected their views. This promoted the principle of social justice and ensured that the researcher fulfilled the emancipatory purpose of the research.

3.10.6 Protection of the Researcher

In line with standard 6.3 of the HCPC Standards of Performance, Ethics, and Conduct (2019), the researcher considered how the research may affect their wellbeing. A risk assessment suggested a low risk to the researcher's emotional wellbeing. However, the researcher remained aware that speaking with the participants may bring back emotive memories from their own childhood experience of SM and, therefore, ensured regular opportunities to reflect on their thoughts and feelings. For example, through seeking regular supervision with their research supervisor. The researcher also maintained a reflective research diary, allowing them to name and explore their feelings away from the participants and their data. This helped the researcher to maintain the aim of the research to explore parents' experiences of SM and for their views to contribute to positive change rather than the researcher's views.

3.11 Validity and Trustworthiness

Lincoln and Guba (1985) espouse that four criteria determine the rigour and trustworthiness of qualitative research. This criteria runs parallel to the criteria used to evaluate quantitative research (see Table 3.6). The researcher kept the criteria in mind throughout the research process and implemented various strategies to meet the criteria, which are discussed in detail below. Due to the emancipatory purpose of the study, catalytic validity is addressed as an additional quality criteria.

Table 3.6

Criteria for Judging the Trustworthiness of Research (Lincoln & Guba, 1985)

	Criteria	
Criteria Number	**Qualitative Data**	**Quantitative Data**
One	Credibility	Internal validity
Two	Transferability	External validity
Three	Dependability	Reliability

Four	Confirmability	Objectivity

3.11.1 Credibility

Credibility is defined as the 'truth value' or the extent to which the data truly represents the views of the participants (Hannes, 2011). To promote credibility, the researcher engaged very closely with the data, transcribing the data themself and repeatedly reading each transcript during the analysis stage. This ensured that the participants' views, thoughts, and feelings (even when subtly communicated) were retained from the interviews to the stage of analysis and interpretation. Furthermore, the researcher included rich descriptions and verbatim quotes to back up the themes identified during the analysis and conducted member checks following the analysis. The researcher emailed each participant's superordinate and subordinate themes to the participant and asked them to provide feedback on whether the themes accurately reflected their views.

3.11.2 Transferability

Transferability is the extent to which the research findings can be generalised to other settings and the wider population (Tobin & Begley, 2004). The small sample size, alongside the reliance on Skype to conduct the interviews, possibly excluding less computer literate parents, limited the transferability of the data. However, as suggested by Smith et al. (2009), providing a transparent context, including detailed demographic information about the parents and their children, will allow individuals to evaluate how similar other members of the SM community are to the participants and whether the findings can be transferred. The researcher also took into account the participant characteristics when discussing the implications of the findings in chapter five to promote accurate transferability.

3.11.3 Dependability

Dependability is equivalent to the concept of reliability, which is the extent to which the research is traceable and logical and can be replicated (Hannes, 2011). The researcher met this criteria through presenting a clear procedure and creating and maintaining audit trails, including a recruitment trail that demonstrates when and how many invitation letters were sent out and when and how many participants volunteered to take part in the research (Appendix F).

3.11.4 Confirmability

Confirmability is the extent to which the research findings are clearly derived from the participants' narratives rather than "figments of the inquirer's imagination" (Tobin & Begley, 2004, p. 392). Owing to the close interaction between the researcher and the participants in qualitative research, there is always a risk of bias (Robson & McCartan, 2016). The researcher's background, individual characteristics, expectations, and past experiences all have the potential to shape their interpretations and must, therefore, be explicitly acknowledged (Thomas, 2017).

To promote the confirmability of the data, the researcher conducted member checks (discussed in section 3.11.1) and actively engaged in reflection and reflexivity throughout the research process, for example by maintaining a research diary and engaging in supervision. As acknowledged in section 3.10.6, these support mechanisms created an 'emotionally safe space' for the researcher to reflect on their thoughts and feelings. They also importantly enabled the researcher to reflect on their own experience of SM and how this had likely shaped their perception of SM, which may have then impacted on how they received and interpreted information from the participants. This enabled the researcher to separate their own views from the participants' views, promoting the researcher's objectivity. Two extracts of the researcher's reflection dairy are presented in Appendix N.

3.11.5 Catalytic Validity

Catalytic validity is the degree to which the research energises and empowers the participants to gain an understanding of reality and promote social change (Reason & Rowan, 1981). The researcher actively promoted this concept from the recruitment stage, for example by highlighting the purpose of the research and desirable outcomes within the information and invitation letter. The use of semi-structured interviews also encouraged the participants to take a lead in the information that they shared and provided them with ample opportunity to talk in detail about their experiences.

3.12 Summary

This chapter has outlined the aims and exploratory and emancipatory purpose of the research, the four research questions, the critical realist ontological, epistemological, and axiological position of the researcher, and the qualitative design of the research and methods of data collection and analysis. Ethical and validity issues have also been addressed. Chapter four presents the research findings.

Chapter 4: Research Findings

4.1 Introduction to Chapter 4

The previous chapter provided an overview of the research methodology, including the use of IPA to analyse each transcript. Chapter four will now present the research findings, predominantly at an individual level due to the purpose of the research to explore the individual lived experiences of parents. Ensuring that each parent is sufficiently 'heard' is also vital in empowering them to contribute to social change, including improvements in support for CYP with SM (consistent with the theory of psychological empowerment [Zimmerman, 1990], as discussed in section 2.4.4). Each theme will be discussed and supported by direct quotations from the participant's transcript (numbers inside the brackets refer to line numbers within the transcript). Themes will then be compared across the participants to identify commonalities and shared experiences. All of the themes for each participant are presented in Appendix O.

4.2 Individual Interview Findings

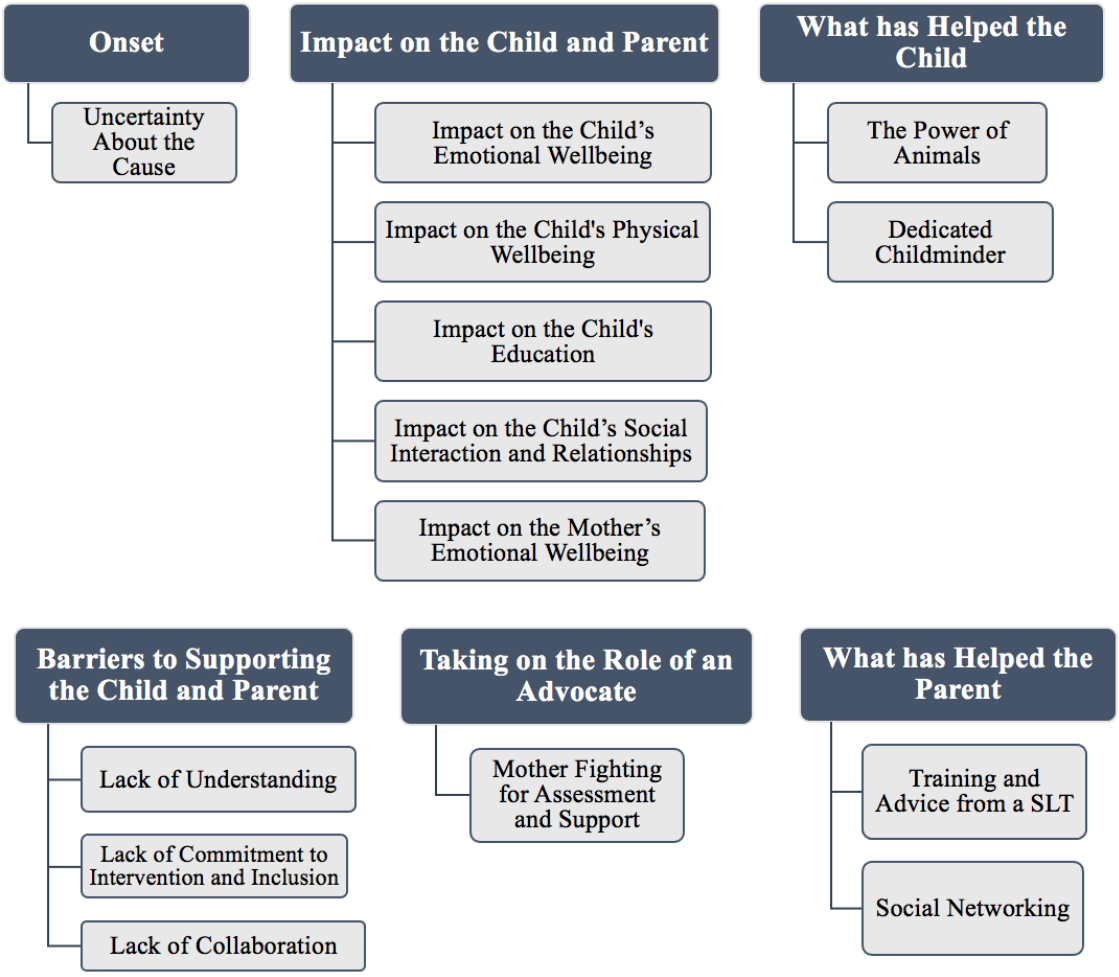
4.2.1 Anna

Anna (41-years-old) is mother to Elizabeth (4.6-years-old [4 years 6 months]), diagnosed with SM at 4.1-years-old (following a diagnosis of ASD). Anna removed Elizabeth from nursery and placed her in the care of a childminder three weeks before the interview following concerns that Elizabeth was not being adequately supported by nursery staff. Elizabeth struggles to speak to adults and children outside of her immediate family other than her childminder.

The superordinate and subordinate themes for Anna are presented in Figure 4.1.

Figure 4.1

Themes from Anna's interview



4.2.1.1. Superordinate Theme 1: Onset. The following theme reflected Anna's understanding of what had led to Elizabeth's difficulty speaking.

4.2.1.1.1. Subordinate Theme 1: Uncertainty About the Cause. Anna explained that she is unsure of what led to Elizabeth's difficulty speaking, questioning whether it could be related to her ASD diagnosis and noting that she has not experienced any trauma: "….I've kind of travelled back with that to think is, did, was there something that happened? But no, nothing" (346-347). Anna has thought long and hard about what might have triggered the SM, perhaps as she believes that finding

the 'answer' will help her to better understand and support Elizabeth. However, the hesitancy in Anna's language suggests that she is still confused.

4.2.1.2. Superordinate Theme 2: Impact on the Child and Parent. The following themes were grouped together as they reflected Anna's experience of the implications of SM.

4.2.1.2.1. Subordinate Theme 1: Impact on the Child's Emotional Wellbeing. Anna explained that Elizabeth's difficulty speaking has reduced her mood and confidence, noting that her self-esteem is "very very low" (590). Anna also shared "….if somebody comes up to her she just shuts down….and you can see the sadness in her…." (449-461). Anna sees a reduction in Elizabeth's emotional wellbeing as a direct consequence of a lack of human interaction. Anna notes that she can "see" the sadness 'within' Elizabeth, implying deep emotional pain.

Anna further reported that whilst attending nursery, Elizabeth's anxiety escalated to the point of her "screaming" (1037) in the night and needing "anxiety medication" (1250). Anna could not believe the extent of Elizabeth's anxiety: "….you shouldn't be anxious like that at 3-years-old, that's mad" (1331-1332).

4.2.1.2.2. Subordinate Theme 2: Impact on the Child's Physical Wellbeing. Anna discussed how Elizabeth struggles to communicate her basic physical needs, such as needing the toilet. Anna reported that whilst in nursery, Elizabeth would "….wet herself or she'd hold it all day, to the point where she was in *extreme* pain" (664-666). Anna suggests that Elizabeth had two options in managing her toileting needs, both of which were detrimental to her dignity and physical health.

Anna also explained that Elizabeth reported physical signs of anxiety and struggled to eat and drink, highlighting the severity of the implications of SM: "….its 'cause she's anxious that she's got a tummy ache and yeah she'd like pick her lunch, barely eat it…." (679-680)

4.2.1.2.3. Subordinate Theme 3: Impact on the Child's Education. Anna reflected on how Elizabeth struggled to settle and engage in nursery: "….her first teacher said 'if I didn't go to her and take her to an activity, she'd stand there for the full six hours just looking at the floor'…." (618-620). Anna implies that Elizabeth would completely withdraw, not even looking up from the floor without adult support.

Anna further spoke about how Elizabeth's difficulty speaking had impacted on her academic progress: "Her levels, erm it impacted on those because she got shocking levels….and she's *really* clever, so that's hard" (535-537). Anna perceives a discrepancy between Elizabeth's academic ability and actual achievement and appears disheartened by this, perhaps as she feels that staff did not do enough to promote Elizabeth's access to learning.

4.2.1.2.4. Subordinate Theme 4: Impact on the Child's Social Interaction and Relationships. Anna noted that SM has affected Elizabeth's ability to interact with relatives and peers and form friendships: "….she hasn't got any friends….she's said to me 'Mummy I would really like a friend….but I don't know how to talk to them' or….'I *can't* talk to them'" (451-455). Anna believes that Elizabeth's difficulty in making friends is not due to a lack of will or motivation, her difficulty speaking is the barrier. This is clearly a key concern for Anna with her noting "I just want her to have a friend" (1849-1850) when discussing her aspirations for Elizabeth.

4.2.1.2.5. Subordinate Theme 5: Impact on the Mother's Emotional Wellbeing. Anna discussed how upsetting it was to see her daughter in distress: "Ohh it was horrendous….." (607) and "….seeing her like that was really upsetting and the fact that she….wants to be able to talk and make friends" (1009-1011). Anna is referring here to Elizabeth's experience of nursery. How Anna closed her eyes and shook her head alongside the first quote suggests that the situation was so emotionally difficult that she cannot bear thinking about it. Anna's distress also seems to reflect her awareness of the turmoil that Elizabeth is experiencing between her desire and actual ability to communicate.

Anna further shared "….you want to rescue them all of the time, but you know to an extent they need to go through those things, because that's how you learn" (1570-1572). Anna appears to be experiencing dissonance between following her natural parenting instinct to protect Elizabeth and her role in promoting Elizabeth's resilience, resulting in herself facing emotional turmoil.

4.2.1.3. Superordinate Theme 3: What has Helped the Child. The following themes illustrated Anna's experience of what has helped Elizabeth to overcome her anxiety.

4.2.1.3.1. Subordinate Theme 1: The Power of Animals. Anna discussed how animals have a "calming" (710) effect on Elizabeth and help her to speak in the presence of others: "….she will sit on the floor and chat to a dog even if it is in room full of people…. (109-110). Anna seems to believe that this is due to the non-threatening nature of dogs, noting "No pressure with a dog is there? [laughs]" (122). Anna's laughter here may represent her disbelief about how the simple presence of a dog can have such a powerful impact.

4.2.1.3.2. Subordinate Theme 2: Dedicated Childminder. Anna reported that the childminder has built a close relationship with Elizabeth and taken on board her advice, resulting in Elizabeth speaking to her: "….she has got a little niche with her already, which is lovely 'cause all that time at nursery that didn't happen…." (102-103) and "….she just listened to what I said" (723). Anna is relieved about the bond that Elizabeth has developed with her childminder, perhaps as she feels that at least one secure relationship is vital to Elizabeth feeling comfortable in an educational setting. Anna also seems to feel heard and valued by the childminder, indicating a more collaborative approach than she experienced with the nursery staff (section 4.2.1.4.2).

4.2.1.4. Superordinate Theme 4: Barriers to Supporting the Child and Parent. The following themes were grouped together as they reflect what has prevented Elizabeth and her mother from being adequately supported.

4.2.1.4.1. Subordinate Theme 1: Lack of Understanding. Anna discussed how the nursery staff struggled to understand Elizabeth's fear of speaking: "….the staff in there would be you know 'oh you can't have your own way Elizabeth'….and you know she's not that kind of child, she's not naughty…." (1004-1007). Anna implies that the staff misinterpreted Elizabeth's silence as a form of defiance. This is further clear through how Anna described the staff as having an "old school attitude" (1013). Anna explained that this resulted in staff "destroying" (1012) Elizabeth, suggesting that they exacerbated her anxiety.

4.2.1.4.2. Subordinate Theme 2: Lack of Commitment to Intervention and Inclusion. Anna reported that the nursery staff consistently failed to implement support strategies, recommended by a Specialist Teacher, and adapt activities to reduce Elizabeth's anxiety and promote her social inclusion:

> ….they were basically told to be non-direct with her, erm, and during the day give her a choice board that she could point to, erm, that never happened….and they have a WOW system where you write on a ticket something that they've done….then they read it out….I said….'for the sake of inclusion can you find a way that she can join in?' and they never did…. (1066-1076)

Anna implies that staff still expected Elizabeth to communicate verbally, and if she was not able to, they simply excluded her from activities.

4.2.1.4.3. Subordinate Theme 3: Lack of Collaboration. Anna reported that the nursery staff did not involve her in supporting Elizabeth: "….the nursery staff kind of thought we're

qualified….you're the mum, you don't kind of really know anything…." (725-728). Anna believes that staff were reluctant to listen to her as they perceived her as less knowledgeable, suggesting that she felt disempowered by her position as a 'mother'.

4.2.1.5. Superordinate Theme 5: Taking on the Role of an Advocate. The following theme represented how Anna has had to be proactive in seeking support.

4.2.1.5.1. Subordinate Theme 1: Mother Fighting for Assessment and Support. Anna discussed how she has had to persistently chase professionals, first to access a diagnosis of SM and then access ongoing support: "….I said 'you know as well as I do, if it's not in black and white these days, you can't get anywhere'" (1412-1413). Here Anna is referring to a conversation that she had with the Speech and Language Therapy Service when trying to access a diagnosis. How direct Anna is in her language highlights how forceful she had to be.

Anna further shared "….I have to keep going and ringing people and being annoying to get what I want…." (1504-1505). This suggests that Anna feels like it is all down to her and her actions to get the support that Elizabeth needs. Through the idiom of "I'm like a dog with a bone" (1513), Anna also suggests that she will not stop 'fighting' until the right support is in place.

4.2.1.6. Superordinate Theme 6: What has helped the Parent. The following themes reflected how Anna has coped with having a child with SM.

4.2.1.6.1. Subordinate Theme 1: Training and Advice from a SLT. Anna discussed how attending a SM training course and receiving ongoing advice from the SLT that delivered the training has been helpful: "….that training course that I booked on was, yeah it was a game changer….she (SLT) validated everything that I said and it made me feel like I could, I had the confidence to do something about it" (1728-1736). The phrase "game changer" suggests that the training was the

turning point for Anna in terms of understanding how to support her daughter. Anna also acknowledges how being heard and understood empowered her to implement this support, perhaps as it enabled her to trust the SLT. Other comments, such as "she's like God" (424), further emphasise how powerful the SLTs input has been.

4.2.1.6.2. Subordinate Theme 2: Social Networking. Anna reported that she has joined various online SM parent support groups and would like to attend a face-to-face support group in her local area to "….just listen to….what the other parents are going through….because sometimes it's nice to talk about it with other people" (1718-1721). Anna acknowledges that she values hearing other parents' experiences, perhaps as this reminds her that she is not alone, which may offer comfort and reassurance.

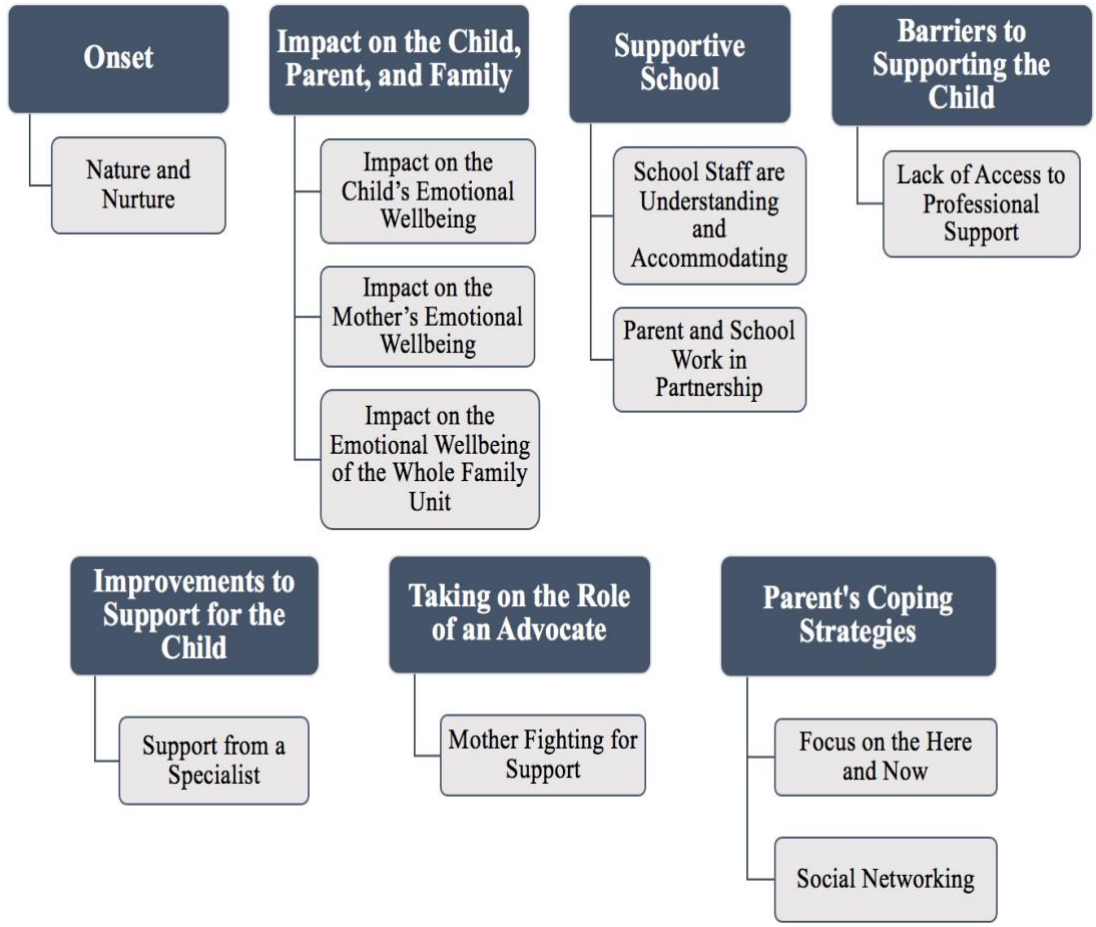
4.2.2 Delia

Delia (46-years-old) is mother to Nikolas (7.7-years-old), diagnosed with SM when he was 5-years-old. Nikolas is in year two of a mainstream primary school and struggles to speak to adults outside of his immediate family, including school staff.

The superordinate and subordinate themes for Delia are presented in Figure 4.2.

Figure 4.2

Themes from Delia's interview



4.2.2.1. Superordinate Theme 1: Onset. The following theme represented Delia's thoughts on what had led to the onset of SM for Nikolas.

4.2.2.1.1. Subordinate Theme 1: Nature and Nurture. Delia reported that Nikolas's difficulty speaking is due to a combination of biological and environmental factors:

> ….we are bilingual….we talk in Greek at home, English everywhere else, and I think that was a bit confusing for him…..second I think Nikolas has innate anxiety, he was born like that….the combination of the two I think led to this." (261-267)

Delia suggests that Nikolas stopped talking due to getting the English and Greek languages mixed up, however she also notes that Nikolas has been anxious from birth. The phrase "innate

anxiety" suggests that Delia perceives genetic factors to have also played a role. It could be that Delia perceives Nikolas's genes as a predisposing factor and bilingualism as a precipitating factor to SM.

4.2.2.2. Superordinate Theme 2: Impact on the Child, Parent, and Family. The following themes were grouped together as they reflect the implications of SM.

4.2.2.2.1. Subordinate Theme 1: Impact on the Child's Emotional Wellbeing. Delia reported that Nikolas has "severe anxiety" (213), which he often expresses through biting his nails and pulling his hair: "….I had to cut his hair because he was threading (pulling) it and, erm, after that he didn't want to go to school, he went with a hat…." (213-215). How Delia talks about cutting Nikolas's hair emphasises the extent of his anxiety. When asked if the hat is a way of Nikolas covering himself, Delia replied "yeah" (226), suggesting that she may see this as a form of self-protection. Wearing the hat may be related to how Nikolas can no longer hide behind his hair as a form of self-protection.

Delia also shared "….he admits that he would like to be like other kids. So that affects him….he doesn't enjoy life as much" (325-327). This suggests that Delia feels like Nikolas is aware of his differences which also affects his emotional wellbeing. Delia feels like her son is missing out on an enjoyable childhood, indicating a sense of injustice.

4.2.2.2.2. Subordinate Theme 2: Impact on the Mother's Emotional Wellbeing. When asked if Nikolas's difficulty speaking has impacted on Delia, she shared "Definitely, it puts stress on me, er, frustration. Erm, it makes life more difficult….because I have to struggle with all of his anxieties as well *plus* the Selective Mutism….it causes me anxiety as well…." (409-418). Delia's choice of words, including "stress", and how she suggests that SM is not a standalone challenge, emphasises the strain on her emotional wellbeing. The phrase "as well" suggests that Delia also sees an interaction between her and Nikolas's anxiety.

Delia further explained that she has a "constant worry" (966) about Nikolas's future and that she often thinks about "disaster scenarios" (972), suggesting that she fears that the situation may spiral, resulting in a more detrimental impact on Nikolas.

4.2.2.2.3. Subordinate Theme 3: Impact on the Emotional Wellbeing of the Whole Family Unit. Delia reported that SM "puts stress on everybody living in the house" (1029) and discussed in detail the detrimental impact on Nikolas's younger sister: "….she copies behaviours that are not good….and I see that sometimes she is stressed and anxious and I think it's just Nikolas's anxiety that is infectious…." (1037-1041). Delia suggests that Nikolas's sister is learning behaviours associated with his anxiety and absorbs his anxiety. Delia uses the word "infectious", implying that Nikolas's anxiety spreads quickly to others.

4.2.2.3. Superordinate Theme 3: Supportive School. The following themes reflect Delia's experience of school staff working hard to support Nikolas.

4.2.2.3.1. Subordinate Theme 1: School Staff are Understanding and Accommodating. Delia explained that school staff understand the phenomenon of SM and allow Nikolas to communicate in a non-verbal manner: "….they totally understand the situation….I think they handle it quite well….his teacher have, er, gave him a board to write few things when he wants to do or ask something, so he communicates in writing" (166-171). Delia implies that staff have been creative and flexible in helping Nikolas to express himself and participate in lessons. Delia also noted that staff understand not to "push him" (526), suggesting that they do not pressure him to speak.

4.2.2.3.2. Subordinate Theme 2: Parent and School Work in Partnership. Delia noted that the school have consistently worked with her to support Nikolas: "….we always discuss everything….they always call me and arrange meetings…." (873-875). When asked if this is helpful,

Delia shared "….yes, because I know what they are facing and they know what I am facing and together we make plans….it's absolutely *brilliant*" (880-882). Delia suggests that working together allows herself and the staff to understand each other's challenges, which then helps to them to problem solve and identify appropriate support. Delia greatly values this collaboration, perhaps as she feels heard and respected.

4.2.2.4. Superordinate Theme 4: Barriers to Supporting the Child. The following theme reflected Delia's difficulty in accessing additional support for Nikolas.

4.2.2.4.1. Subordinate Theme 1: Lack of Access to Professional Support. Delia noted that Nikolas has been referred to CAMHS but is still waiting to be seen and also shared "….I would like him to be seen by a Psychologist, Paediatric specialist, and this hasn't happened and I understand that it's not possible to happen…." (704-706). Delia extended on this by saying "….we don't have that in this country apparently…." (568-569), suggesting that alternative professionals have not been brought to her attention. When asked if the school had mentioned EP support, Delia replied "no they haven't" (578).

4.2.2.5. Superordinate Theme 5: Improvements to Support for the Child. The following theme reflected the additional support that Delia believes Nikolas needs.

4.2.2.5.1. Subordinate Theme 1: Support from a Specialist. Consistent with section 4.2.2.4.1, Delia shared "….I need a Paediatric Psychologist to properly assess him and guide me….because however much you read on the internet, no matter how many books you read, you don't have the experience of a professional" (780-784). Delia suggests that she can only gain so much knowledge through her own research and that she has got to the point where she needs the insight of a specialist

to inform her next steps. This suggests that Delia feels lost about what to do and perhaps even concerned about doing more harm than good.

4.2.2.6. Superordinate Theme 6: Taking on the Role of an Advocate. The following theme represented Delia's determination and drive to get the support that Nikolas needs.

4.2.2.6.1. Subordinate Theme 1: Mother Fighting for Support. Delia discussed how all of the support that Nikolas has received is a result of her efforts: "….if I hadn't called this private, er, Speech and Language Therapist nothing would have been done….after I had this, erm, diagnosis….I pushed the GP to refer me to a Paediatrician, so everything had to come from *me*…." (598-601) and "….I have to fight for everything…." (942). Through the words "pushed" and "fight", Delia conveys how forceful she has had to be, for example in getting professionals to make the right referrals. Without this effort Delia believes that Nikolas would be in a worse situation, suggesting that she believes that being a powerful advocate is a necessity. Delia also communicates this belief through the advice that she would give to other parents of children with SM: "….keep fighting to get the support they need, because otherwise nobody will come and give them support…." (1012-1014).

4.2.2.7. Superordinate Theme 7: Parent's Coping Strategies. The following themes reflected how Delia has coped with supporting a child with SM.

4.2.2.7.1. Subordinate Theme 1: Focus on the Here and Now. When asked what helps Delia to manage her worry, she shared "Just day by day, there's not much you can do can you? Really just everyday hope you get a good day, not a bad day. I try to deal with whatever comes" (982-984). This was interpreted as Delia accepting the situation for what it is and trying to solve challenges on a day-to-day basis rather than thinking about the future, perhaps as this reduces her catastrophising thoughts (discussed in section 4.2.2.2.2).

4.2.2.7.2. Subordinate Theme 2: Social Networking. Delia further explained that she has joined an online SM support group, as she finds it helpful to hear the views of other parents and also adults with SM:

> ….I find it helpful reading stories, similar stories of other parents….and….I find, erm, testimonies very useful, from people with Selective Mutism….having other people with the same problem telling me what they would like to happen and how they need to be treated, I find it invaluable…. (989-998)

Delia specifically refers to parents with a "similar" experience, perhaps as this reminds her that she is not alone and provides emotional comfort. Speaking to adults with SM seems to provide a different function, helping Delia to step into Nikolas's shoes to recognise what support he needs. Therefore, 'social networking' may be an emotion-focused and problem-focused coping mechanism for Delia.

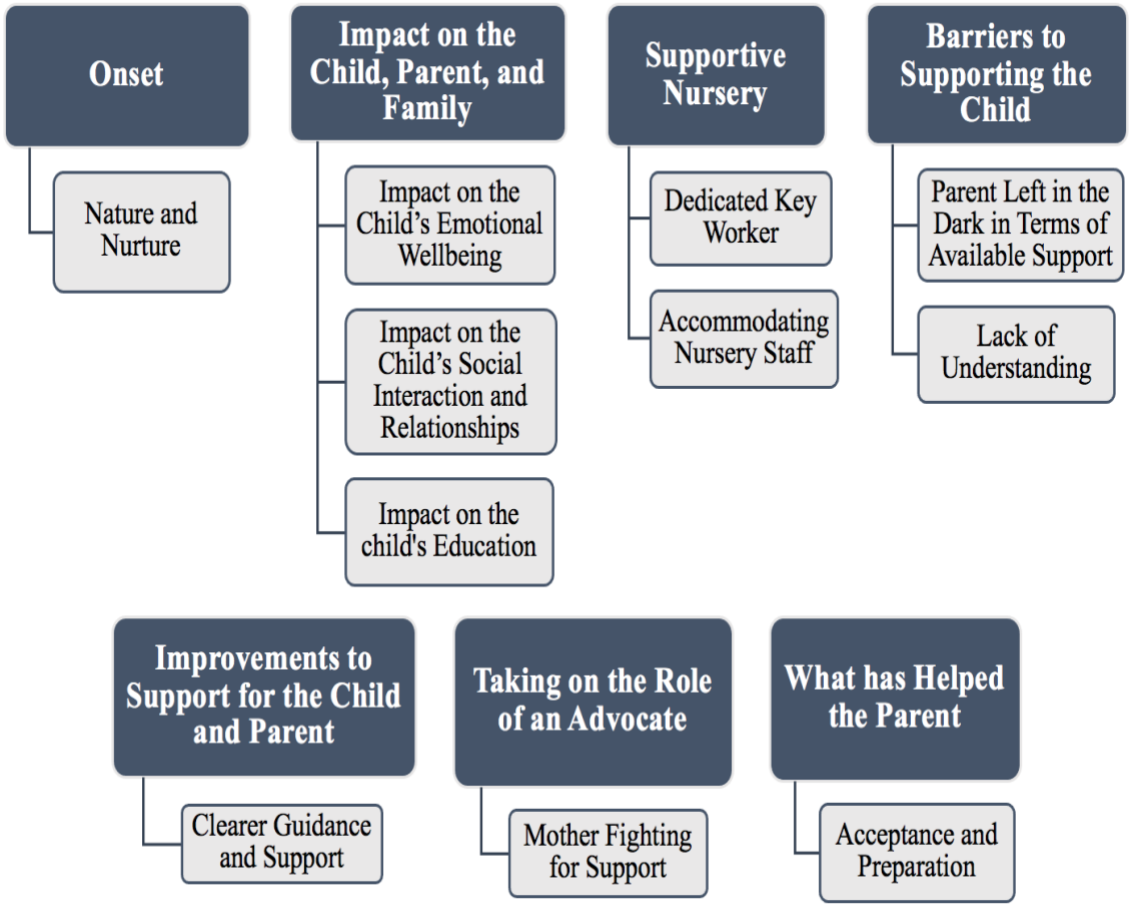
4.2.3 Vicky

Vicky (36-years-old) is mother to Mia (3.5-years-old), diagnosed with SM when she was 2-years-old. Mia attends a private day nursery and can speak to her key worker and a select number of peers, but struggles to speak to anyone else outside of her immediate family.

The superordinate and subordinate themes for Vicky are presented in Figure 4.3.

Figure 4.3

Themes from Vicky's interview



4.2.3.1. Superordinate Theme 1: Onset. The following theme represented Vicky's thoughts around what has led to Mia's difficulty speaking.

4.2.3.1.1. Subordinate Theme 1: Nature and Nurture. Vicky reported that Mia's difficulty speaking is related to a combination of a family history of similar difficulties, indicating a possible genetic element, and Mia's temperament and personality:

> He (Mia's Father) had a bit of anxiety as a child, not to this extent, but he certainly just had trouble speaking initially at school. Erm, and then I think secondly….I don't know, can you say it's her in a sense?….her individuality….like nature and nurture, but just her…. (262-271)

Vicky struggles to comprehend and explain the role of Mia's personality, suggesting that SM is "just her". However, Vicky later expanded on this by explaining that Mia is "fearful" (309) and "sensitive" (313). How Vicky refers to Mia's personality as the second contributing factor suggests that she sees Mia's genes as the predisposing factor and her personality traits as the precipitating factor to SM.

4.2.3.2. Superordinate Theme 2: Impact on the Child and Parent. The following themes were grouped together as they represented Vicky's experience of the implications of SM.

4.2.3.2.1. Subordinate Theme 1: Impact on the Child's Emotional Wellbeing. Vicky explained that Mia often appears scared when around other people: "….she just sort of says that she is scared, scared of people….we've got a friend of ours….every time we see him she hides under our dining table" (562-566). Vicky emphasises the extent of Mia's fearfulness by noting that she "hides" in some social situations, suggesting that she goes into a 'flight' mode, perhaps as a form of self-protection.

Vicky further noted that Mia feels "sad" (573) about her difficulty speaking and that she is concerned about the long term impact on Mia's mental health: "….we just need to keep an eye out for depression and isolation and stuff in the future…." (540-542)

4.2.3.2.2. Subordinate Theme 2: Impact on the Child's Social Interaction and Relationships. Vicky reported that Mia struggles to interact and form close relationships with adults and peers: "….she knows what friendships should be like….and….she'll be making things and doing all these for her lovely best friend, but doesn't have the ability to say 'hello'….she wants to talk, but just can't….(510-517) and "….it's like she's invisible, no one is going to see her if she just stands there and can't say anything" (534-536). Vicky implies that Mia has the understanding and motivation needed to make and maintain friendships but struggles to do so due to her difficulty speaking. Vicky

describes Mia as "invisible", suggesting that she believes that Mia is at risk of being forgotten by her peers. This may be feeding into her concern about Mia becoming isolated in the future (section 4.2.3.2.3).

4.2.3.2.3. Subordinate Theme 3: Impact on the Child's Education. Vicky discussed how Mia's difficulty speaking has acted as a barrier to her learning: "….she basically sat sideways to the class (phonics class), couldn't join in….when the songs about you know learning their phonics, you know have all the singing and dancing actions, there is no way that she can do that" (476-480). Vicky suggests that Mia particularly struggles to engage in activities where there is an expectation to communicate (through vocalisation and gesture). Vicky is worried about how this might affect Mia's academic progress when she starts school, noting that Mia will "get behind quite quickly" (484-485), perhaps as she feels that the emphasis on learning through communication will only increase.

4.2.3.3. Superordinate Theme 3: Supportive Nursery. The following themes reflected Vicky's experience of nursery staff doing as much as they can to support Mia.

4.2.3.3.1. Subordinate Theme 1: Dedicated Key Worker. When asked what support from nursery has been most helpful, Vicky replied:

> ….just the way the key worker took the time initially….to build up that trust and relationship….for her to feel comfortable going to pre-school….was the biggest and best thing, because now they can keep working on the next steps and getting her interacting…. (904-912)

Vicky emphasises how vital the trusting and secure relationship that Mia's key worker has built up with her by suggesting that this has reduced her anxiety and provided the foundation for Mia to continue to overcome her fear of speaking. Vicky's perception of the key worker as a source of

security is also clear through her other comments, for example "….she just keeps an eye out for her over the day…." (832). Vicky believes that Mia is constantly 'held in mind' by her key worker.

4.2.3.3.2. Subordinate Theme 2: Accommodating Nursery Staff. Vicky also spoke about how the staff have remained mindful of Mia's fear of speaking and made adaptations in the setting to reduce her anxiety: "….they are doing everything they can to just help settle her in…." (703-704) and "….whenever we arrived everyone would be in that room, but as soon as we came they would break out into her room for a while….that just helped settle her" (772-780). Vicky's comments suggest that she feels that Mia's wellbeing is a priority for staff with them adapting a whole setting routine to help her to feel comfortable. Vicky appears reassured by this, noting that she is "happy" (1035) with the staff's response.

4.2.3.4. Superordinate Theme 4: Barriers to Supporting the Child. The following themes were grouped together as they represented Vicky's difficulties in accessing additional support for Mia.

4.2.3.4.1. Subordinate Theme 1: Parent Left in the Dark in Terms of Available Support. Vicky explained that she is unsure of what additional support she could access: "I was actually thinking….just to speak to the SENCo to see what's actually available….so it's more what else can we do? Is there anything else available? I didn't push it, I didn't even think that there would be something…." (854-860). Vicky's desire to speak to the SENCo, along with her rhetorical questions, indicates a lack of transparency around avenues of support. Vicky suggests that she would have fought for support had she known what was available, indicating a sense of disempowerment.

4.2.3.4.2. Subordinate Theme 2: Lack of Understanding. Vicky noted that both relatives and staff (in Mia's previous nurseries) have struggled to understand SM: "….there has always been the

signs there….and any time I raised it I was just kind of told 'oh don't worry, they will grow out of it, they are shy….'" (61-64). Vicky suggests that her concerns were not initially taken seriously with staff normalising and downplaying Mia's anxiety, attributing it to Mia being shy and "just sensitive" (363), which she would overcome by herself with time.

4.2.3.5. Superordinate Theme 5: Improvements to Support for the Child and Parent.

The following theme reflected Vicky's view of what else could help her to support Mia.

4.2.3.5.1. Subordinate Theme 1: Clearer Guidance and Support. Consistent with section 4.2.3.4.2, Vicky explained that she would like greater clarity on which intervention strategies to implement:

> ….it'd be really good to know really what the, the pathway is….what are the strategies to do at each stage….if you get the right things happening at the pre pre-school and the pre-school stage then that's going to help with the school. (1061-1069)

Vicky would like a list of recommended intervention strategies for each stage of Mia's education as she believes that this will allow earlier intervention, resulting in fewer challenges as Mia moves through her education.

Vicky also discussed how it would be helpful for professionals to be transparent about whether they can offer support with SM:

> ….it would be nice to know that….the professional or specialist that you are going to has an interest in SM and knowledge on SM….they are all not the same in each profession and it's having that person with that knowledge….I think would be really helpful. (1128-1142)

Vicky understands that professionals have varying degrees of knowledge of SM and shows a preference to seek support from those with greater expertise, perhaps as she feels that they are more likely to understand and take her concerns seriously and be more committed to identifying support strategies.

4.2.3.6. Superordinate Theme 6: Taking on the Role of an Advocate. The following theme represented how Vicky has actively sought support for Mia.

4.2.3.6.1. Subordinate Theme 1: Mother Fighting for Support. Following on from section 4.2.3.4.1, Vicky reported that she has taken it upon herself to look for a private SLT to access support: "….I have looked up and I've seen there is a Speech and Language Therapist….SM is one of her specialities….I might just give her a try, just to see if there is something that we can get started on now…." (614-620). The repetition of "I" emphasises Vicky's self-reliance in seeking support. Vicky's phrase "get started on now" implies that she has sought this support to be proactive, tackling SM before Mia starts school. Vicky's belief in the importance of parents being proactive was also clear through the advice she would give to other parents: "….when you know that something's not quite right, get onto it" (1085). This may be related to Vicky's previous challenge in getting nursery staff to take her concerns seriously, delaying early intervention.

4.2.3.7. Superordinate Theme 7: What has Helped the Parent. The following theme represented Vicky's primary coping strategy.

4.2.3.7.1. Subordinate Theme 1: Acceptance and Preparation. When asked how Vicky has coped with Mia's difficulty speaking, she replied "….it is what it is….it's just knowing, thinking about the future, being aware of any potential depression, bullying, all of those sorts of things that could come up and….just being aware of it….then you do the best you can" (1187-1192). Similar to Delia, Vicky's phrase "it is what it is" suggests that she believes that there is not a lot she can do other than accept the phenomenon. However, Vicky copes by also thinking about all possible eventualities, perhaps as this helps her to continue to be proactive in understanding Mia's needs and seeking the right support.

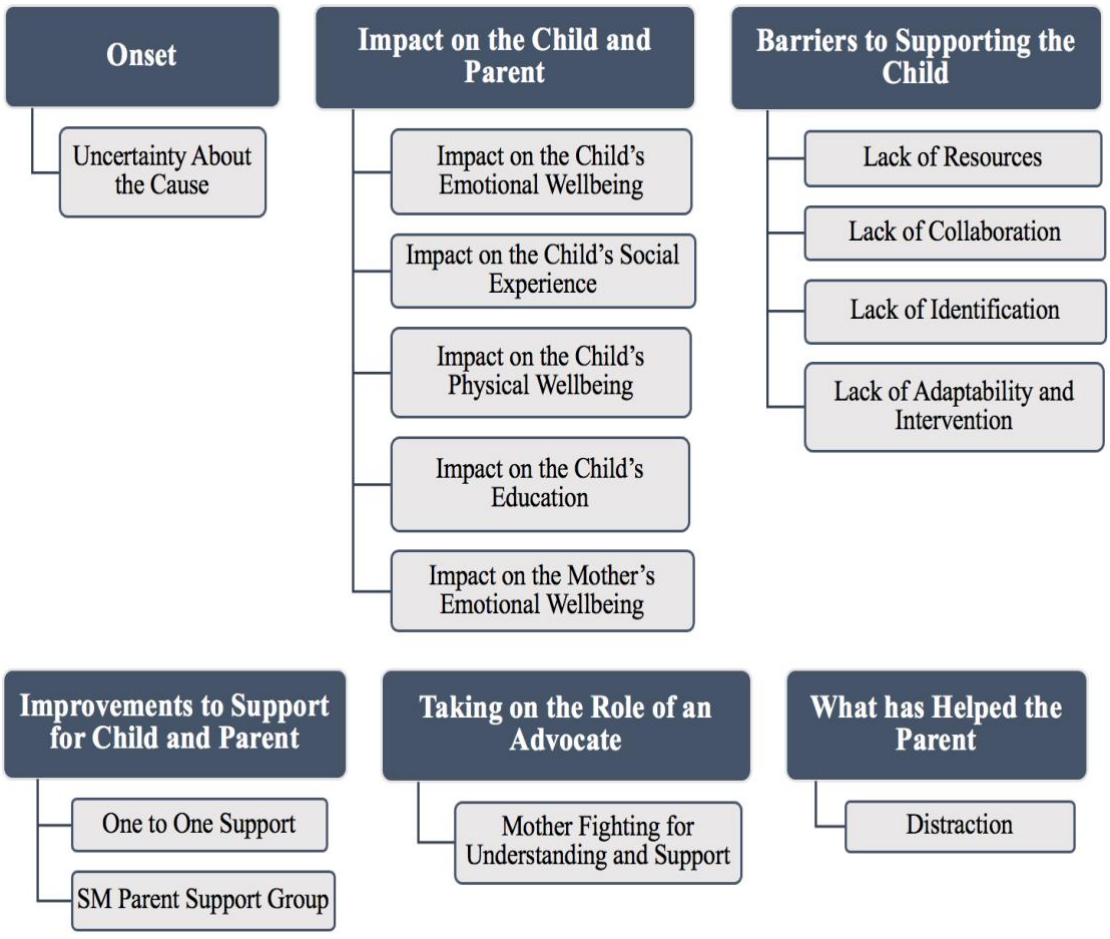
4.2.4 Laura

Laura (31-years-old) is mother to Grace (7.4-years-old), diagnosed with SM when she was 7-years-old. Grace is in year two of a mainstream primary school and struggles to speak to all adults and children outside of her immediate family.

The superordinate and subordinate themes for Laura are presented in Figure 4.4.

Figure 4.4

Themes from Laura's interview



4.2.4.1. Superordinate Theme 1: Onset. The following theme reflected Laura's understanding about what might have caused Grace's difficulty speaking.

4.2.4.1.1. Subordinate Theme 1: Uncertainty About the Cause. When asked what had led to the onset of SM for Grace, Laura replied "….I really don't know….'cause I'm really confident and outgoing and I talk a lot and I talk to everybody. Her brother is exactly the same…." (505-507). Through noting how herself and her son are the opposite to Grace and later explaining that there is no family history of anxiety and SM, Laura appears to rule out genetic factors. Laura also reported "….there's been no upheaval in her life…." (495), ruling out environmental triggers.

4.2.4.2. Superordinate Theme 2: Impact on the Child and Parent. The following themes were grouped together as they reflected the implications of SM.

4.2.4.2.1. Subordinate Theme 1: Impact on the Child's Emotional Wellbeing. Laura reported that Grace's difficulty speaking has "….1000 percent…." (622) lowered her confidence and that Grace struggles to cope with associated challenges, including peer bullying (section 4.2.4.2.2) and a difficulty in making academic progress (4.2.4.2.4): "….she *always* compares herself to other children, erm like ____(Name of Child) for instance is on teddy bear twenty-one, she's on teddy bear four….she feels silly, she feels inadequate….it just makes the whole situation worse…." (1268-1273) and "Even comments, they really hurt her….everything deeply hurts her, she has got no ability to sort of brush it all off…." (775-776). Laura implies that Grace feels less competent than her peers and is embarrassed by her difficulty talking and the implications of this on her learning, which exacerbates her anxiety. Laura also suggests that Grace takes unpleasant comments to heart, believing what others say and struggling to re-build her confidence, indicating a lack of resilience.

4.2.4.2.2. Subordinate Theme 2: Impact on the Child's Social Experience. Laura explained that Grace has "….never *ever* spoken…." (335-336) to extended relatives and struggles to interact and form relationships with peers: "….she doesn't play with friends, she's always sort of on the side-lines looking in, but you can see she so much wants a best friend like any little girl does" (580-582).

Laura suggests that although Grace has friends, she cannot deepen her relationships to form a 'best friend' due to struggling to join in with their play. However, Laura believes that Grace's peers have also not helped by giving up on interacting with her: "….they know that she won't talk, so they just don't bother" (616-617).

Laura further explained that Grace has been bullied: "….a little boy pulled her hair out, like ripped it out and Grace didn't tell anybody all day…." (410-412). Laura changes the word "pulled" to "ripped", emphasising the aggressive nature of the incident, and also emphasises Grace's vulnerability by highlighting how she was unable to notify anybody.

4.2.4.2.3. Subordinate Theme 3: Impact on the Child's Physical Wellbeing. Laura noted that Grace's anxiety results in physical discomfort, including "….stomach aches…." (724), and that she struggles to communicate her physical needs, for example struggling to say when she is hurt:

> ….there was an incident at home where she touched the cooker and she'd burnt her fingers….she didn't say anything and then when my friends had left like two hours later she come and she just burst out crying….so she was holding all of that pain in for *hours*. (148-155)

Laura's emphasis on "hours" may reflect an element of disbelief about how significant Grace's fear of speaking is, preventing her from reaching out even when in pain. Laura went on to discuss similar incidents, suggesting that this is a common challenge.

4.2.4.2.4. Subordinate Theme 4: Impact on the Child's Education. Laura discussed how Grace struggles to access learning and has "….always been behind…." (653-654) academically as a result of her difficulty speaking: "….she doesn't know how to read, she doesn't know how to write….she doesn't know how to do anything, because she will not ask for help" (261-268). Laura relates Grace's difficulty in acquiring basic academic skills to a challenge in asking for help,

suggesting that this is the causal mechanism in the link between SM and Grace's lack of academic progress.

Laura further discussed how Grace "….doesn't like…." going to school (1384) and how it is difficult to get her into school, noting "….she'll just cling onto me…." (1148-1149). Laura's choice of language emphasises how Grace struggles to detach herself from Laura, which Laura may believe is down to being Grace's "safety blanket" (1637). Grace may feel more anxious within the school setting due to Laura not being present.

4.2.4.2.5. Subordinate Theme 5: Impact on the Mother's Emotional Wellbeing. When asked if Grace's difficulty talking causes herself to feel anxious, Laura replied "Majorly….then that affects Grace, because she can see that I'm anxious" (814-815). Laura highlights a bi-directional relationship between her anxiety and Grace's anxiety, suggesting that their anxiety may be intertwined.

Laura also shared "….it makes me feel crap, it makes me feel like a rubbish Mum, putting her in situations where actually it's not benefitting her…." (801-803) and "….some days I'm *so* depressed, just because….I feel like I'm abusing my daughter.…" (1279-1281). How Laura refers to herself as "abusing" Grace by sending her into school in an anxious state suggests that she feels like she is letting Grace down and causing greater harm, indicating immense guilt. Such emotional strain is also likely related to how Laura reported that she does not get "….any time" (1635) to herself due to being Grace's "….safety blanket" (1637) and Grace struggling in the care of others. Laura explained that she has even had to "….quit college…." (904).

4.2.4.3. Superordinate Theme 3: Barriers to Supporting the Child. The following themes were grouped together as they represented factors that have prevented Grace from being adequately supported.

4.2.4.3.1. Subordinate Theme 1: Lack of Resources. Laura explained that school staff have struggled to implement support due to a lack of funding:

> ….even with the recommendations from the Speech and Language Therapist, something like the teacher having to know about Selective Mutism, like they said that's an impossible ask. So although they sort of accept it….their hands are tied on what they can do. (1008-1013)

Laura further reported "….I think the school's only excuse is and it's not just this school….all of their excuses are there's no money…." (1687-1690). Laura's metaphor "their hands are tied" conveys a belief that staff are restricted in what they can do regardless of their knowledge and professional advice. In Laura's eyes funding is the most powerful determiner of support.

4.2.4.3.2. Subordinate Theme 2: Lack of Collaboration. Laura reported that the school have never met with her to discuss Grace's needs and have not kept her informed about what support they have accessed: "….apparently they've had a phone call about Grace, months and months ago, but I'd never heard that …." (1323-1324). Laura is referring to how the school sought advice from an EP but did not make her aware until much later, preventing her from contributing to decisions and assisting with interventions. Here Laura may be feeling disempowered by her position as a parent.

4.2.4.3.3. Subordinate Theme 3: Lack of Identification. Laura discussed how school staff have struggled to recognise the severity of Grace's difficulty speaking: "….the school have never really been proactive in doing *anything*….because she's a good child, she doesn't cause any fuss….the TA in her class, and this has *stuck* with me….she said Grace's like the forgotten child…." (184-191). Laura believes that Grace has gone 'under the radar' due to a lack of externalising difficulties, which may pose a greater challenge for staff. Learning that Grace is the "forgotten child" is something that Laura has never let go, perhaps as it evoked a strong sense of injustice and emotional pain. This is likely given Laura's following comment: "….that really hurt my heart…." (192).

4.2.4.3.4. Subordinate Theme 4: Lack of Adaptability and Intervention. Laura reported that staff have introduced one visual strategy to allow Grace to communicate her emotions but have not made any other adaptations or implemented any interventions: "….I don't actually feel like they've given me any real help or supported her in any which way….they could have done a lot lot more" (285-288). Laura believes that the support offered by the school has been inadequate and may feel let down due to her belief that with more effort and planning, staff could have been much more supportive.

4.2.4.4. Superordinate Theme 4: Improvements to Support for Child and Parent. The following themes reflected the support that Laura believes herself and Grace would benefit from.

4.2.4.4.1. Subordinate Theme 1: One-to-One Support. Laura discussed how Grace would benefit from one-to-one support: "….they need that one-to-one that is just there for them that they can emotionally rely on….that one-to-one would get them through their whole school career…." (1794-1797). The importance of a dedicated adult may reflect Laura's understanding that she helps Grace to manage her anxiety by acting as a "….safety blanket" (1637) and that Grace needs a similar source of safety within school.

4.2.4.4.2. Subordinate Theme 2: SM Parent Support Group. Laura explained that she would like to attend a SM parent support group because "….like I said I'd never heard anything about it before and it has been really tough" (1565-1566). Laura relates her desire to network with other parents to how "tough" her experience has been, suggesting that she hopes that it will allow her to share the emotional strain and engage in joint problem solving.

4.2.4.5. Superordinate Theme 5: Taking on the Role of an Advocate. The following theme represented how Laura has had to push for Grace to be understood and supported.

4.2.4.5.1. Subordinate Theme 1: Mother Fighting for Understanding and Support.

Laura reported that she took it upon herself to refer Grace to an independent SLT for a diagnosis: "….the school take ages, NHS takes forever and realistically her going back to year three, there was going to be no change….so I needed to do something…." (938-941). Laura believes that relying on wider systems to identify Grace's needs would have only delayed intervention.

Laura also explained that she has had to fight for teachers to implement support: "….*I* said to the teachers I want a meeting with them every beginning of term to see what they're gonna put in place…." (1071-1073). Through emphasising "I" Laura makes it clear that the termly meetings were her idea. Her intent behind the meetings is to also ensure that the staff actually plan ways forward, promoting Grace's best interests.

4.2.4.6. Superordinate Theme 6: What has Helped the Parent. The following theme conveyed how Laura has coped with Grace's difficulty speaking.

4.2.4.6.1. Subordinate Theme 1: Distraction. When asked how Laura supports her own emotional wellbeing, particularly after dropping Grace off at school, she explained "….for six hours I just, I tidy up to try and forget about it all…." (1654-1655). Laura suggests that she tries to distract herself by tidying up, perhaps as this stops her from catastrophising when Grace is at her most vulnerable (at school). The fact that Laura does this for six hours highlights the intensity of her anxiety and suggests that she lacks additional coping mechanisms.

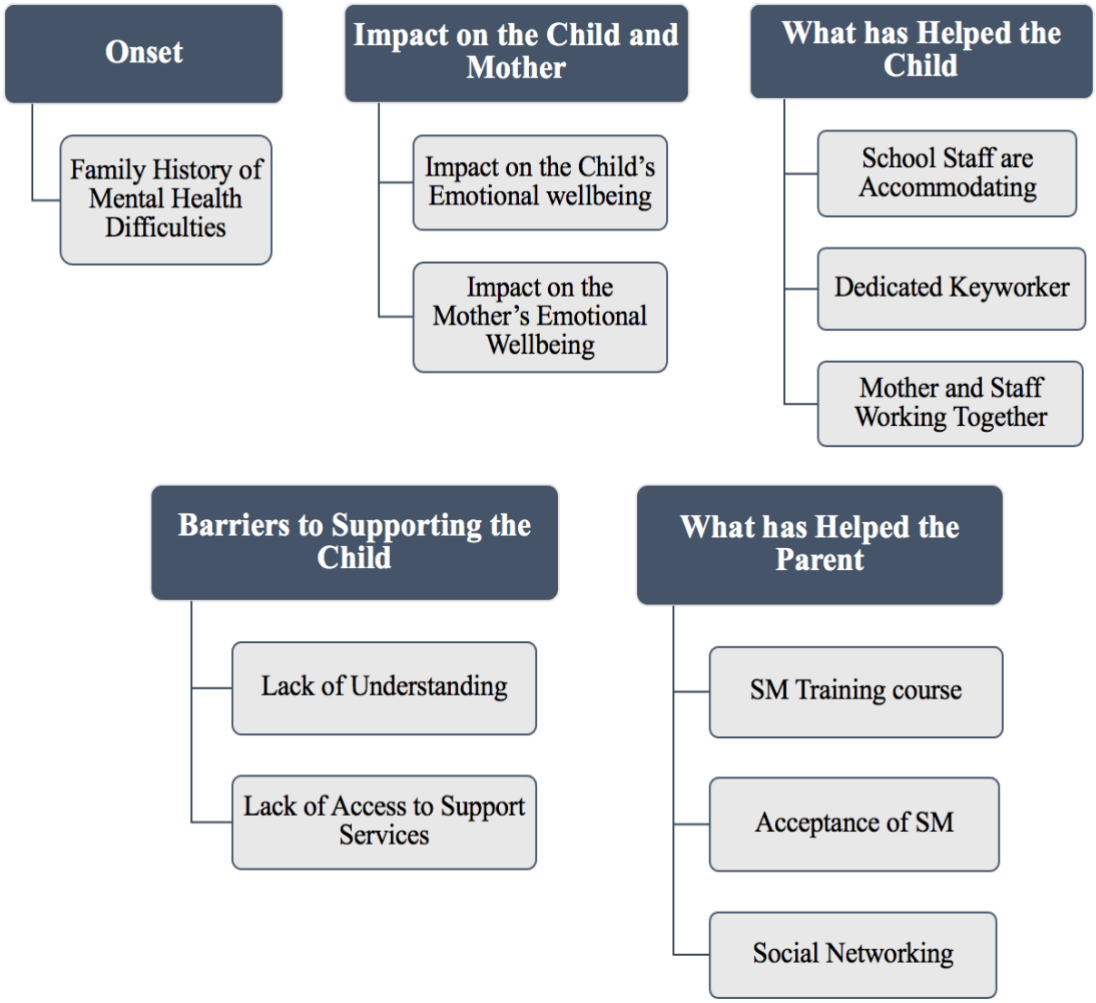
4.2.5 Charlotte

Charlotte (45-years-old) is mother to Oliver (7.5-years-old), diagnosed with SM when he was 5-years-old. Oliver is in year two of a mainstream primary school (along with his identical twin). Oliver speaks to his peers and key worker at school but struggles to speak to everybody else outside of his immediate family.

The superordinate and subordinate themes for Charlotte are presented in Figure 4.5.

Figure 4.5

Themes from Charlotte's interview



4.2.5.1. Superordinate Theme 1: Onset. The following theme explored Charlotte's understanding of the cause of SM.

4.2.5.1.1. Subordinate Theme 1: Family History of Mental Health Difficulties. Charlotte shared "….there is definitely anxiety and, erm, depression in the family….it must pass down through the generations….so I think probably a genetic thing more than anything….he's *just* more predisposed to anxiety…." (310-341). Charlotte believes that genetic factors are the primary trigger

to Oliver's difficulty talking due to a family history of anxiety and depression. However, Charlotte also discussed how Oliver's personality may have played a role, noting that his twin is "….completely the opposite" (347), appearing "….totally uninhibited…." (347-348).

4.2.5.2. Superordinate Theme 2: Impact on the Child and Mother. The following themes were grouped together as they reflected the impact of SM.

4.2.5.2.1. Subordinate Theme 1: Impact on the Child's Emotional Wellbeing. Charlotte explained that Oliver is "….happy…." (373) but lacks confidence: "….he's got confidence issues….the two kind of go hand in hand, so it's his confidence that holds him back rather than his not speaking…." (367-369). Charlotte suggests that Oliver's difficulty speaking and lack of confidence are closely related and that his lack of confidence can be the bigger burden, perhaps now maintaining his difficulty speaking.

4.2.5.2.2. Subordinate Theme 2: Impact on the Mother's Emotional Wellbeing. Charlotte discussed how she worries about Oliver, becoming more worried each time he moves up a school year: "….towards the end of every school year I do start to fret a bit more, because I think….who, what's the teacher going to be like next year, erm, is ____(Key Worker's Name) still going to be assigned to him…." (571-574). Charlotte's worry is related to uncertainty about continued support and how new staff will react, perhaps due to her experience of staff struggling to understand SM (section 4.2.5.4.2). It could also be related to Charlotte's concern that the implications of SM might worsen as Oliver gets older: "….in the future it could really affect how he progresses through life, his performance at school, erm and then getting a job as well" (363-365). Charlotte's thoughts seem to snowball with her noting that it could affect Oliver's academic progress, which could then limit his life chances in adulthood.

4.2.5.3. Superordinate Theme 3: What has Helped the Child. The following themes were grouped together as they reflected Charlotte's experience of helpful support.

4.2.5.3.1. Subordinate Theme 1: School staff are Accommodating. Charlotte reported that the school have introduced alternative ways for Oliver to communicate and have utilised the close relationship he has with his key worker to promote his access to learning: "….he will read out loud to her (key worker) and then they kind of assess him that way" (429-430).

Charlotte also noted that the staff were "….very accommodating" (159) in response to her request for Oliver to be kept in the same class as his twin to reduce his anxiety.

4.2.5.3.2. Subordinate Theme 2: Dedicated Key Worker. Charlotte discussed how Oliver's key worker (a Speech and Language Mentor) has been a key source of support: "….most of its come from ____(Key Worker's Name) really and, and you know her pushing to work closely with him" (611-613) and "…._____(Key Worker's Name) has spoken to all the teachers involved and sort of tried to raise awareness within the school of Selective Mutism" (735-737). Charlotte suggests that the key worker has initiated the majority of support, for example taking the lead on the sliding-in intervention, trying to "….slide other teachers in…." (702). However, the words "….pushing…." and "….fight…." (117) imply that the key worker has had to be forceful in delivering support, perhaps having to persuade other staff members to allow her to work with Oliver. Charlotte also suggests that the key worker has educated others about SM, suggesting that she may see the key worker as Oliver's advocate.

4.2.5.3.3. Subordinate Theme 3: Mother and Staff Working Together. Charlotte discussed how she and Oliver's key worker attended SM training together and initially co-delivered the sliding-in technique. Charlotte also shared:

> ____(Key Worker's Name) will keep me informed of what's going on, so she'll just pop out to the playground….and have a chat with me, erm, just to keep me up to date with what's been happening….. if there is any progress….. (782-786)

Charlotte feels like the key worker keeps her in the loop about how Oliver is coping in school and the impact of her support.

4.2.5.4. Superordinate Theme 4: Barriers to Supporting the Child. The following themes were grouped together as they reflected factors that have made it difficult for Oliver to access support.

4.2.5.4.1. Subordinate Theme 1: Lack of Understanding. Charlotte reported that there is "….very little awareness…." (1237) about SM and that relatives have particularly struggled to understand, resulting in unhelpful responses: "….he refused to say thank you for some food and she (relative) denied him a dessert….I was like 'nooo that's the worst thing you can do, don't punish him for not speaking'" (1102-1110). Charlotte suggests that Oliver's relative misinterpreted his silence as rudeness, resulting in her punishing him. Charlotte is mortified by this, describing it as the "worst thing", perhaps as such punishment only exacerbates and maintains Oliver's anxiety.

Charlotte also discussed how she only found out about Oliver's difficulty speaking through "….a comment in passing…." (170) four months after he had started nursery, suggesting that she believes that staff did not recognise the significance of this and the importance of early intervention.

4.2.5.4.2. Subordinate Theme 2: Lack of Access to Support Services. Charlotte discussed how she has struggled to access support from specialist services, noting that the school have "….stopped investing…." (812) in the Speech and Language Therapy Service.

Charlotte also shared "….I kind of got the impression when, when he was diagnosed that it was kind of there you go, there's your diagnosis, it's over to you now…." (868-870). Charlotte

believes that all responsibility to help Oliver was placed on her shoulders immediately following Oliver's diagnosis, suggesting that she has had no choice but to become the 'expert'.

4.2.5.5. Superordinate Theme 5: What has Helped the Parent. The following themes reflected Charlotte's coping mechanisms.

4.2.5.5.1. Subordinate Theme 1: SM Training Course. Similar to Anna, Charlotte had recently attended a SM training course and shared "….the training was just fantastic….just everything slotted into place….everything that they said in the training was yeah, yep that's my child, that makes sense, yeah that's exactly what's been happening. And so it was really *good* to be told how you can think about *dealing* with it" (1022-1028). Charlotte suggests that the course enabled her to gain a better understanding of her son and validated all of her views, offering comfort and reassurance. Charlotte's emphasis on "good" and "dealing" also conveys how much she valued receiving guidance on intervention strategies, perhaps as it resulted in her feeling more equipped to support Oliver.

4.2.5.5.2. Subordinate Theme 2: Acceptance of SM. Charlotte discussed how she has come to terms with the phenomenon of SM: "….we've just learnt to live with it. Erm, I don't think about it too much" (508-509) and "….we're just gonna to have to try to work through it…." (562-563). Charlotte's phrase "learnt to live with it" conveys how she has become accustomed to Oliver's difficulty speaking rather than constantly fighting it. Charlotte also tries to avoid rumination, focusing on working through each challenge as it occurs, perhaps as this prevents her from feeling overwhelmed.

4.2.5.6.3. Subordinate Theme 3: Social Networking. Charlotte explained that she has joined various online SM parent support groups and when asked if helpful, replied "….yeah. People put recommendations on there, books to read, and things like that…." (914-915). Charlotte suggests that

the groups increase her knowledge of SM, including what support strategies to put into place. Charlotte also shared "….it's good to be able to talk to other people in the same situation" (1059-1060), highlighting how much she values shared experiences, perhaps learning over time that people are more understanding and supportive in this instance.

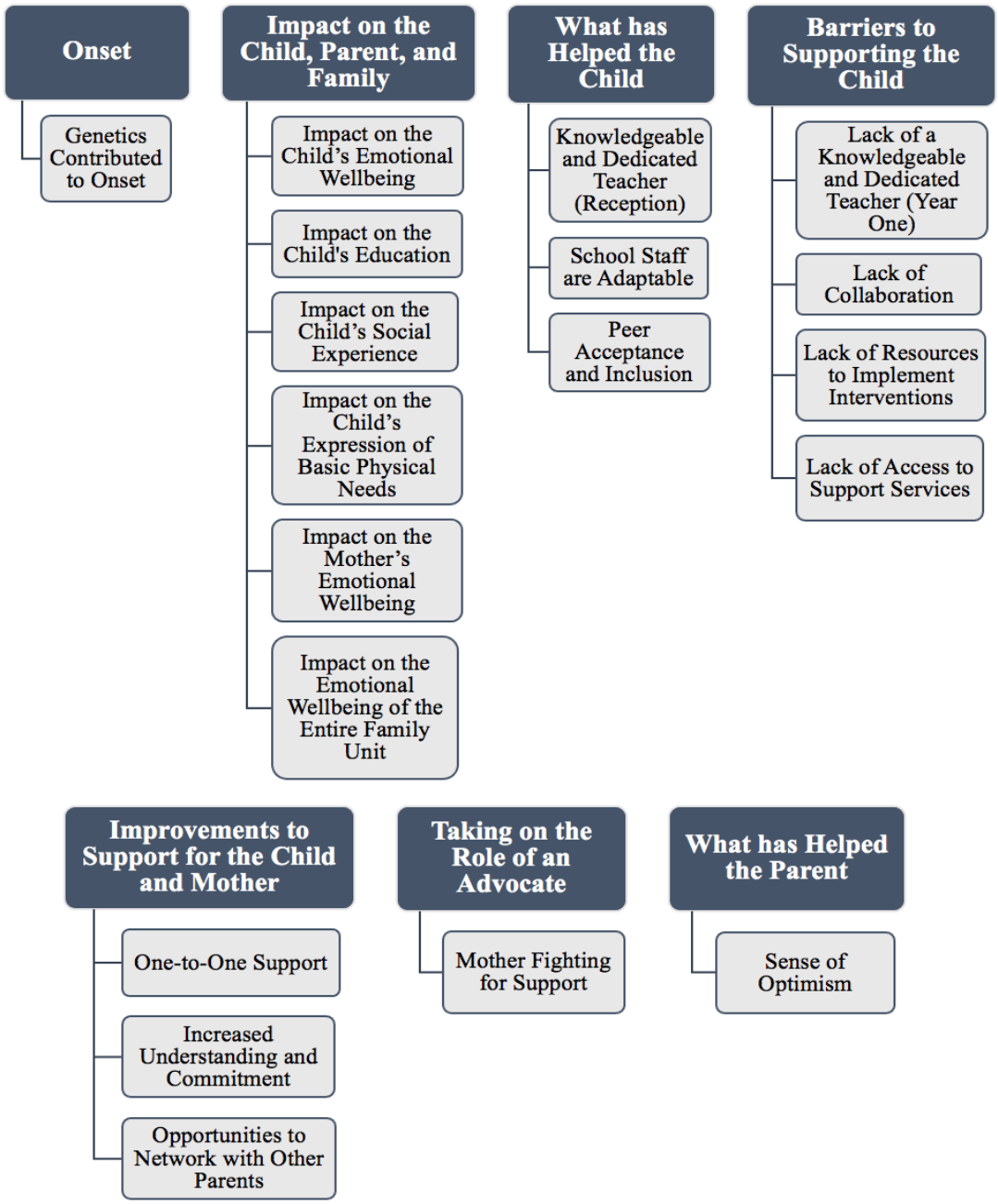
4.2.6 Steph

Steph (39-years-old) is mother to Hazel (6.4-years-old), diagnosed with SM when she was 4-years-old. Hazel is in year one of a mainstream primary school and struggles to speak to most adults and children outside of her immediate family.

The superordinate and subordinate themes for Steph are presented in Figure 4.6.

Figure 4.6

Themes from Steph's interview



4.2.6.1. Superordinate Theme 1: Onset. The following theme reflected Steph's thoughts on what had contributed to Hazel's difficulty speaking.

4.2.6.1.1. Subordinate Theme 1: Genetics Contributed to Onset. When asked what had led to Hazel's experience of SM, Steph shared:

> ….the jury's out slightly on whether anxiety can be genetic or not, but I think it might be for her because she was showing signs of it from *such* a very young age and….I am someone who suffers with anxiety and so is her dad…. (515-520)

Steph believes that Hazel is genetically predisposed to anxiety due to appearing anxious early on in life and a close family history of anxiety. Steph also rules out environmental triggers, noting that they had a "….good attachment…." (528) from birth and that Hazel was "….socialised from straight away…." (528-59).

4.2.6.2. Superordinate Theme 2: Impact on the Child, Parent, and Family. The following themes were grouped together as they conveyed Steph's experience of the impact of SM.

4.2.6.2.1. Subordinate Theme 1: Impact on the Child's Emotional Wellbeing. Steph discussed how Hazel's difficulty speaking and associated challenges, including peer bullying (section 4.2.6.2.3), has had a detrimental impact on her emotional wellbeing: "….so she was having….these *meltdowns*…." (223-224) and "….she was *so* unhappy….we were getting woken up twice a night for an hour each time with her just screaming and crying….every single day I picked her up from school she'd come out looking really angry…." (886-890). Steph is referring to how Hazel presented in reception and at the start of year one. Steph's words and phrases, including "meltdown" and "every single day", emphasises the extent and persistent nature of Hazel's distress. Steph also noted that Hazel was "….*utterly* exhausted…." (1748), which she may believe contributed to the 'meltdowns', particularly after "….holding it together all day (at school)…." (1745).

4.2.6.2.2. Subordinate Theme 2: Impact on the Child's Education. Steph discussed how Hazel has struggled to reach her academic potential: "….she's a bright girl, but she's behind because it's hard work working when you're anxious…." (394-395) and "….she doesn't read to the teacher, so they haven't really been able to assess her reading level…." (607-608). Steph's reference to

learning being "hard" may reflect her understanding that anxiety can eat away at Hazel's energy levels (discussed in section 4.2.6.2.1), reducing her capacity to focus. Steph also notes that SM can prevent Hazel from demonstrating her academic knowledge, which she may feel is also contributing to her low levels.

Steph further discussed how Hazel was reluctant to attend school up until recently: "….she'd be undressing herself as quickly as I could get her dressed and saying 'I'm not going to school'….leaving home crying….it was just *awful*" (894-897). The school routine was an emotional and physical battle for Steph with Hazel doing whatever she could to avoid going into school.

4.2.6.2.3. Subordinate Theme 3: Impact on the Child's Social Experience. Steph explained that Hazel struggles to interact with adults and peers and has been "….delayed…." (574) in forming friendships, only recently making a friend: "….she did stand on her own, ohh it's heart breaking, she used to say to me 'I just wander around on my own'…." (802-803). Steph is referring to how Hazel would be isolated at playtimes. Recalling this memory seems to be emotionally painful, perhaps as it reminds Steph of just how unhappy and vulnerable Hazel was.

Steph further highlighted Hazel's social vulnerability by discussing how she had been bullied by some year six pupils: "….they'd said [sighs]….'because you don't speak you're gonna have to stand on a stage in front of the whole school and a timer will be set for five minutes and you have to speak'….she was in such a state…." (214-218). Steph's sigh may indicate an element of disbelief about how the pupils tapped into Hazel's "….biggest insecurities…." (249-250) in order to make the most distressing comments.

4.2.6.2.4. Subordinate Theme 4: Impact on the Child's Expression of Basic Physical Needs. Steph reported that Hazel struggles to communicate her physical needs in school, such as when she needs a drink or to go to the toilet: "….we've tried you know you can hold this pebble and you get it out if you need the loo….but she can't…." (153-155). Steph notes that Hazel is unable to

communicate her needs even in a non-verbal manner, which has sometimes resulted in Hazel "….wetting herself…." (741), affecting her dignity.

4.2.6.2.5. Subordinate Theme 5: Impact on the Mother's Emotional Wellbeing. Steph discussed how Hazel's difficulty speaking has had a detrimental impact on her own emotional wellbeing:

> ….she just seemed so depressed and just, it's just absolutely hideous seeing your little child unhappy….and it's been hard standing at the school gates with parents with children who don't have Selective Mutism….and then really feeling *bad* because I'd feel *annoyed* with their conversations….. (871-880)

Steph's language suggests that she found the situation unbearable. Steph also felt frustrated by other parents, perhaps due to a strong sense of injustice that their children were not experiencing such difficulties, resulting in guilt.

Steph further discussed the toll that Hazel's 'breakdowns' took on her, noting that she sometimes felt "….exasperated" (1775), and sharing: "….I had a bit of a breakdown….Hazel had just been going on and on and I was just *tired* and didn't know what to do really. And I, erm, I had a bit of a panic attack…." (901-905) and "….it was really hard [tearful]…." (921-922). Steph's choice of words, along with her tears, emphasises the extent of her distress in response to the ongoing challenges associated with Hazel's anxiety and feeling so helpless. Steph also noted that she had to take "….a month off work…." (923) and go on "antidepressants" (929), suggesting that the stress affected her everyday functioning.

4.2.6.2.6. Subordinate Theme 6: Impact on the Emotional Wellbeing of the Entire Family Unit. Steph reported that she has previously worried about the impact on Hazel's sister: "….when things were really really bad I used to think oh god what is this doing to her, because there was so much unhappiness and so much screaming and shouting…." (977-979). Steph believes that when

Hazel's anxiety was at its highest, the atmosphere at home was tense and unpleasant, which Hazel's sister may have picked up on. Steph also wondered if how Hazel's sister had struggled to settle into pre-school was related to her witnessing how upset Hazel becomes at school drop-off.

Steph further noted that the situation has taken a "….toll…." (1571) on her relationship with Hazel's father due to needing to focus all of her time and energy on Hazel.

4.2.6.3. Superordinate Theme 3: What has Helped the Child. The following themes were clustered together as they reflected Steph's views on helpful support.

4.2.6.3.1. Subordinate Theme 1: Knowledgeable and Dedicated Teacher (Reception). Steph discussed how Hazel's reception teacher has been a key source of support:

> ….her reception teacher was amazing and kind of already knew that's what it was….and was already kind of implementing things that are useful…..they (other teachers) all just kind of listened to this initial teacher….they just kind of went with what she said about it. (388-399)

Steph believes that the teacher was proactive, drawing on her understanding of SM to implement support prior to Hazel's diagnosis, and that she educated other staff.

4.2.6.3.2. Subordinate Theme 2: School Staff are Adaptable. Steph discussed various adaptations that the school have made to lower Hazel's anxiety: "….she's allowed to play in a different playground….with a smaller number of children…." (1095-1096) and "….they won't sort of put her on the spot and expect her to do anything in big groups…." (1143-1144). Steph believes that the staff understand the importance of not pressuring Hazel to speak and interact and have removed this pressure by adapting classroom and wider school practices, for example not expecting her to engage in group work.

4.2.6.3.3. Subordinate Theme 3: Peer Acceptance and Inclusion. Steph discussed how Hazel is more able to speak around peers who acknowledge her but do not expect her to speak and "….don't make a big fuss…." (683-684) when she does speak, suggesting that she is more comfortable when peers accept her for who she is.

Steph also discussed how Hazel has benefitted from making a friend: "….a month before lockdown, they got really friendly and she even said to me twice….'I actually think I like school a bit now', which was like oh my gosh" (821-823). Steph's phrase "oh my gosh" conveys a sense of disbelief and excitement about the significant impact that having a friend has had on Hazel's experience of school.

4.2.6.4. Superordinate Theme 4: Barriers to Supporting the Child. The following themes were clustered together as they represented factors that have prevented Hazel from being adequately supported.

4.2.6.4.1. Subordinate Theme 1: Lack of a Knowledgeable and Dedicated Teacher (Year One). Steph reported that Hazel's current teacher has not fulfilled "….*any*...." (427) of her requests to develop his knowledge of SM and is not committed to implementing support, including the sliding-in technique: "….the sliding in….(pause)….hasn't been that great, because he basically just kept leaving the classroom and not coming back…." (438-440) and "….it's a real shame that he's not made more effort….she could have had a better year if she'd had like her previous teacher…." (1730-1733). Steph conveys her frustration and disappointment with the teacher by suggesting that Hazel has missed an opportunity to make further progress in overcoming her fear of speaking due to his lack of effort.

4.2.6.4.2. Subordinate Theme 2: Lack of Collaboration. When Steph was asked if she has regular meetings with Hazel's school, she replied "no" (1108) and shared "….they don't really invite

us in…. I am in email contact when I need to be, erm, but that's, that's about it really" (1263-1265). Steph suggests that she is the one who usually initiates contact with the school, suggesting that they do not actively seek her involvement in supporting Hazel.

4.2.6.4.3. Subordinate Theme 3: Lack of Resources to Implement Interventions. Steph reported that herself and school staff have struggled to find time to implement support, including the sliding-in technique: "….in reception the teachers were so lovely and wonderful and really wanted to do it, but they were *too* busy…." (462-464) and "….that manual (SM support manual) is really helpful….but it seems to ignore the fact that you might have a job or any other members of your family [laughs]" (1353-1355). Steph perceives discord between staff wanting to help and their actual ability to help, believing that the situation is as frustrating for them as it is for her. Steph's humorous take on the manual may reflect her disbelief in how she is expected to deliver such intensive support when as a parent she already has multiple competing demands.

4.2.6.4.4. Subordinate Theme 4: Lack of Access to Support Services. Steph discussed how Hazel has been turned down for support by the school nursing team, CAMHS, and the Speech and Language Therapy Service, and shared "….there doesn't seem to be, erm, very many services that are interested in Selective Mutism….people seem to have either never heard of it or, or they're not interested….or…..their service doesn't cover it" (1346-1350). Steph perceives a gap in provision for CYP with SM due to a lack of awareness of the phenomenon and professionals not prioritising it as an area of need.

4.2.6.5. Superordinate Theme 5: Improvements to Support for the Child and Mother. The following themes were grouped together as they illustrated what additional support Steph feels would be beneficial.

4.2.6.5.1. Subordinate Theme 1: One-to-One Support. When asked what support Hazel would benefit from, Steph replied "….this is a massive dream, but, erm, if she could have one-to-one support at school….if she could have a year of that, doing you know proper sliding in but with the same person…. she would be away…." (1364-1368). Steph believes that support from one dedicated adult would provide the foundation for Hazel to overcome her fear of speaking but that this is unlikely to happen, perhaps due to her experience of a lack of resources (section 4.2.3.4.2).

4.2.6.5.2. Subordinate Theme 2: Increased Understanding and Commitment. Steph discussed how school staff need to learn more about SM and plan and allocate time to deliver interventions: "….what I really need for them to do is go here we go this is, this protected time for Hazel's teacher to do this….and let's, let's sit down and go through how we're going to do this" (1285-1288). Through using the word "need", Steph implies that the process of Hazel's teacher being given time to solely focus on Hazel is a necessity as she cannot see it happening otherwise.

4.2.6.5.3. Subordinate Theme 3: Opportunities to Network with Other Parents. Steph noted that she would find it helpful to speak to other parents of children with SM: "What I would really like is to like just meet up with someone who's going through it….and just go 'oh isn't this awful?'….and just to have someone go 'I know', 'cause you just feel like people don't get it…." (1487-1495). Steph's comments, including her rhetorical question, suggest that this would allow her to share the emotional burden and access validation, which may offer reassurance that she is doing the best she can.

4.2.6.6. Superordinate Theme 6: Taking on the Role of an Advocate. The following theme represented Steph's fight for Hazel's needs to be met.

4.2.6.6.1. Subordinate Theme 1: Mother Fighting for Support. Steph reported that she has had to push for the school to support Hazel: "….I've realised over the last couple of years that….you have to be pushy" (1063-1064) and "….no one else is gonna to do it, so you have to" (1725-1726). Steph recognises that she has no choice but to advocate for Hazel's best interests. This is something that Steph has learnt over time, suggesting that she has repeatedly encountered others failing Hazel and things only improving with her involvement.

4.2.6.7. Superordinate Theme 7: What has Helped the Parent. The following theme reflected Steph's primary coping mechanism.

4.2.6.7.1. Subordinate Theme 1: Sense of Optimism. Steph discussed how she remains hopeful about the trajectory of Hazel's difficulty speaking: "….she can be….really funny and very confident in certain situations, so it's, erm, you know every time I see that….I'm like….you've got this in you….you'll get there" (1615-1623). Steph often sees glimpses of Hazel's true personality, which reminds her that she has got what it takes to overcome SM. Steph seems certain about this: "it will happen with time and patience and support" (1632-1633).

4.3. Findings Across Participants

As described in chapter three, the last stage of the analysis was to look for patterns in experiences across the participants by printing out the superordinate and subordinate themes for each participant on different coloured paper and re-grouping the themes based upon commonalities (demonstrated in Appendix P).

Some experiences were unique to certain participants, whilst other themes could be combined and relabelled to represent multiple participants' experiences. For example, the superordinate themes of 'what has helped the child' and 'what has helped the parent' were combined with 'improvements to support', resulting in the following two superordinate themes: 'sources of support for the child'

and 'parental coping strategies'. This then represented those parents who had already experienced specific elements of effective support and ways of coping, and those who had not but reported would be helpful. In accordance with this change, some subordinate themes were pulled together and relabelled. For instance, 'dedicated childminder', 'dedicated key worker', 'knowledgeable and dedicated teacher', and 'one-to-one support' were pulled together and relabelled 'a dedicated adult'.

Only the most common themes (occurring across at least 50% of the participants) were taken forward for validity purposes, resulting in six superordinate themes, presented in table 4.1 and outlined below. These themes are discussed and further interpreted in relation to the research questions in chapter 5.

Table 4.1

Themes Generated During the Whole Group Analysis

Themes		Participants Contributing to the Theme					
Superordinate Theme	**Subordinate Theme**	**Anna**	**Delia**	**Vicky**	**Laura**	**Charlotte**	**Steph**
Complex Onset	Nature and Nurture		✓	✓		✓	✓
Pervasive Impact	Impact on the Child's Emotional Wellbeing	✓	✓	✓	✓	✓	✓
	Impact on the Child's Social Experience	✓		✓	✓		✓
	Impact on the Child's Education	✓		✓	✓		✓
	Impact on the Child's Ability to Meet and Express Physical Needs	✓			✓		✓
	Impact on the Mother's Emotional Wellbeing	✓	✓		✓	✓	✓
Available and Helpful Sources of Support	Accommodating Nursery/School Staff		✓	✓		✓	✓
	A Dedicated Adult	✓		✓	✓	✓	✓
	Parent and Staff Working in Partnership	✓	✓			✓	
Challenges in Accessing Support	Lack of Recognition and Understanding	✓		✓	✓	✓	
	Lack of Collaboration	✓			✓		✓

	Lack of Commitment to Intervention	✓			✓		✓
	Lack of Access to Support Services		✓			✓	✓
Parent Taking on the Role of an Advocate	Mother Fighting for Support	✓	✓	✓	✓		✓
Parental Coping Strategies	Social Networking	✓	✓		✓	✓	✓
	Specialist Input	✓	✓			✓	
	Acceptance		✓	✓		✓	

4.3.1. Superordinate Theme 1: Complex Onset

Four participants discussed how they feel that their child is genetically predisposed to anxiety and SM. Charlotte, Steph, and Vicky reflected on how there is a close family history of anxiety which may have contributed. For example: "….there is definitely anxiety and, erm, depression in the family, so mental health illness. My dad suffered….I guess it must pass down through the generations.…I've had phobias in the past that I've had to have treatment for…." (Charlotte, 310-317) and "….I totally get that I could have influenced that and I am someone who suffers with anxiety and so is her dad, so you know if you're gonna have a genetic predisposition than she would (Steph, 515-521). Moreover, whilst Delia reported that there is not a family history of anxiety, she referred to her son's experience of anxiety as being "innate" and "intrinsic" (264-266) and reported that he had appeared anxious from birth, indicating a possible biological basis of his difficulty speaking.

However, three of these participants also reflected on how environmental factors may have contributed, resulting in the subordinate theme of 'nature and nurture'. For example, Delia reflected how she believes that her son's experience of SM was triggered by a combination of genetics and bilingualism:

> First is that we are bilingual, he is bilingual, er, I mean we talk in Greek at home, English everywhere else, and I think that was a bit confusing for him initially as a toddler….second I think Nikolas has innate anxiety, he was born like that, he, was, was difficult baby….so he has intrinsic anxiety that is not helping and the combination of the two I think led to this (Delia, 261-267)

Charlotte also reflected on how her son's personality must have played a role due to how his identical twin (who he shares his genetic makeup) has not experienced anxiety and SM: "If you look at his brother, he's completely the opposite. His brother is *totally* uninhibited…." (Charlotte, 346-348).

4.3.2. Superordinate Theme 2: Pervasive Impact

All participants reported that their child's difficulty speaking has had a detrimental impact on their self-esteem and four participants reported that it has, at times, reduced their mood. For example, "….she lacks confidence" (Steph, 705), "….she's just a bit scared and also may be a little bit sad by it all" (Vicky, 572-573), and "….like last September when she was just so unhappy and she was very unhappy all through the summer holidays before, 'cause I think she was just dreading going back to school….it was *awful*, she just seemed so depressed…." (Steph, 866-872).

Three parents also discussed how SM has evoked a high level distress for their child: "….she was crying out in the night…." (Anna, 71), "….she worries about everything, she's such a little panicker" (Laura, 718-19), and "….she can take hours to get to sleep….and she will say 'my hearts beating too quickly' and I'll check and it's not, but it's that feeling of anxiety I guess…." (Steph, 1649-1653).

Five parents further noted a significant impact of their child's difficulty speaking and associated challenges (for example, struggling to access recognition and support), on their own emotional wellbeing. For example, describing their child's inability to express themselves and emotional distress as "horrendous", "upsetting" (Anna, 1009-1010), and "hideous" (Steph, 872), and noting that they sometimes feel "very stressed" and "very frustrated" (Delia, 964). Laura also shared: "….it's very very difficult emotionally, more than anything else….all ever, all any parent wants their children to be in life is happy and healthy, when your child's got Selective Mutism you know that they're not happy….". Laura normalises her wish for her daughter to be happy through using the phrase "all any parent wants" and makes it clear that seeing her daughter unhappy is an emotional strain.

Moreover, Anna reflected on how she has particularly found it difficult to cope with a lack of understanding by relatives and staff and also staff and professionals failing to take her concerns seriously:

> "….it can be quite stressful if you're dealing with people that don't really understand it or if anyone says 'oh it might go away on its own', 'cause when you're at that point where you're *desperate* for help, when your child is being broken and people are going 'oh it might go away on its own', that's really annoying to hear…."
>
> Some parents also related their stress to a fear about what will happen in the future:
>
> ….I have a constant worry about the future….we have a constant worry about what's gonna happen when he becomes a teenager….when the other children notice that he is kind of different, that will definitely affect his friendships, er, and that will make his anxiety and frustration worse and so on and so on. And you starting all these disaster scenarios like every parent, I try to control that, but you know it's not easy, it can be quite difficult sometimes…. (Delia, 964-974)

Here Delia reflects on how she tries to stop herself from catastrophising but that as a parent this is very challenging.

One parent further related her distress to having no choice but to send her daughter into school despite her daughter finding this setting highly anxiety-provoking: "….every single day I take her into school it feels like I'm a bad parent. I often walk away crying in my car, I just feel like leaving her there is horrendous…." (Laura, 746-748).

Overall, these findings lead to the subordinate themes of 'impact on the child's emotional wellbeing' and 'impact on the mother's emotional wellbeing'.

In addition, half of the participants reported that the phenomenon has acted as a barrier to their child expressing and meeting their basic physical needs, including going to the toilet, seeking help when they have hurt themselves or are in discomfort or pain, and being able to eat and drink. For example, Laura shared "….she won't tell me if she has hurt herself if anybody is around…." (677-678) and "….for two days she was walking around in these brand new shoes, only for me two days later to find out that she still had cardboard in the shoe" (1620-1622), whilst Anna shared "….she

would say 'Mummy I couldn't eat my lunch, because my knickers were wet' or she would say 'I couldn't eat my lunch 'cause I had a tummy ache'" (673-675).

Half of the participations also reported that the phenomenon of SM has acted as a barrier to their child interacting with others, including relatives. For example, Anna shared "….I think it took about a year with my Mum. She came nearly every day for. She would shut down for about an hour to start with and then she would warm up, but it took a long long time" (488-491). Anna is referring here to how it took her daughter a significant amount of time to build up the ability to speak to her grandmother. Vicky also reflected on how SM has affected her daughter's ability to build up a relationship with her grandparents: "….it also impacts the relationship that she has say with her grandparents….in theory that should be a really lovely relationship, but you know although it's there, it's quite different to what the grandparents were hoping for…." (446-455).

Half of the participants further reported that SM has had a detrimental impact on their child's ability to interact with nursery/school staff and peers and make friends. For example, Laura noted: "….she doesn't talk to any children" (140) and "Birthday parties, she won't go and play, she'll stand by my side" (169), whilst Steph shared "….she has been very delayed in being able to make friendships…." (574-575). Laura and Steph also explained that their child has been bullied, suggesting that they are socially vulnerable.

Moreover, half of the participants reflected on how their child's anxiety and difficulty talking has acted as a barrier to their learning and academic progress. For example, Steph shared "….I think she's a bright girl, but she's behind because it's hard work working when you're anxious isn't it?" (394-395) and "….she's probably not a brilliant reader, *but* I think she is far less good at it than she would be if she was more confident…." (577-579). Vicky also discussed how her daughter has struggled to engage in activities requiring verbal communication, including phonics classes: "….she basically sat sideways to the class (phonics class), couldn't join in…." (476-477).

Laura and Steph further reported that their children have been reluctant to attend school, suggesting that they are at risk of emotionally-based school refusal. For example, Laura noted

"….Grace will not let go of my hand (at the school gates)" (1142) and "she doesn't like it (school) at all, she doesn't, she doesn't like it" (1388-1399). Steph provided similar accounts and described how staff have to physically detach her daughter from her every morning: "….she would say 'I'm not going, I'm not going, I'm not going' and she quite often has to be you know, I have to pull her hands off mine and someone has to hold her hand and take her away" (1046-1048).

Overall, these findings resulted in the subordinate themes of 'impact on the child's ability to meet and express physical needs', 'impact on the child's social experience', and 'impact on the child's education'.

4.3.3. Superordinate Theme 3: Available and Helpful Sources of Support

Four participants discussed how nursery and school staff are trying to reduce their child's anxiety by making adaptations to the environment and routines and introducing alternative communication strategies. Delia explained, for example, that staff communicate with her son through writing and the use of gestures: "….the teachers ask him usually questions that can be answered with 'yes' and 'no', so he shows one hand for 'yes', the other hand for 'no', and Nikolas choose hand, or if he wants to say something more complicated he uses his board and writes down" (353-357).

Three participants also reported that their child is benefitting from being supported by one consistent staff member. For example, Charlotte discussed how her son's Speech and Language Mentor has educated other members of staff about SM and ensured the consistent delivery of interventions, including the 'sliding in' technique. Furthermore, Vicky discussed how having a consistent keyworker has enabled her daughter to communicate her basic needs and desires:

> "There's one staff member, her key worker, who sort of did *huge* amounts of effort when we first went there (nursery) to settle her in and sort of have her trust her. Erm, so she doesn't speak a huge amount to her, but enough to tell her she needs to go to the toilet, erm, what she wants, if somebody is doing something that she doesn't like…." (139-145).

Two participants also expressed a wish for their child to receive "….one-to-one…." (Laura, 1794; Steph, 1365) support from a member of staff in order to build up their child's emotional security and promote a more consistent approach to intervention. For example, Laura shared:

> "….they need that one-to-one that is just there for them that they can emotionally rely on and I feel like that one to one would get them through their whole school career, I do….always there for them, you know 'cause then they've got their friend" (1794-1804).

Half of the participants further noted that staff are working closely with them to understand and support their child. For example, by taking their advice on board: "….she (childminder) just listened to what I said….when I said do a running commentary and don't ask her any questions, she really went along with that" (Anna, 723-725), and keeping them up-to-date about their child's progress in overcoming their difficulty speaking: "….she'll (mentor) just pop out to the playground in the afternoon and have a chat with me….she's also got a contact book that she writes in as well…." (Charlotte, 782-788).

Overall, these findings resulted in the following subordinate themes: 'accommodating nursery/school staff', 'a dedicated adult', and 'parent and staff working in partnership'.

4.3.4. Superordinate Theme 4: Challenges in Accessing Support

Half of the participants reported that relatives and nursery and school staff have struggled to understand the significance of their child's difficulty speaking and make necessary adaptations. For example, Anna discussed how staff in her daughter's previous nursery continued to place expectations on her daughter to speak despite being aware of SM: "….even though they (staff) were meant to have had training, they would come out every morning and go 'hello Elizabeth, how are you?' and you would be like ohh [sighs] and we've talked about this, don't do that…." (612-615). The way in which Anna sighs here suggests that the lack of adaptation by staff was a source of frustration. Moreover, Vicky reported that nursery staff initially downplayed her daughter's anxiety, delaying identification and intervention: "….she'd cry at drop-off *every* single time…..again they'd say 'oh some people are

just sensitive and just need a bit more, just upset'…." (361-364) and "….they'd keep saying 'oh it's fine, it's what happens, they all you know cry, some cry more than others, just go'…." (403-404). Laura also discussed how staff still currently expect her daughter to participate in activities in school that she finds most anxiety-provoking, including school plays and sports days: "….she's still got to participate in sports day and that's really hard for her, because it's in front of all of those people…." (1467-1468).

Half the participants further reported that staff have not worked in collaboration with them to plan or implement support. For example, Laura discussed how the school sought advice from an EP without her knowledge and also shared "…so they haven't really mentioned what they can do for her at the moment or what they're gonna put in place for her" (1214-1215), suggesting that staff have not involved her in planning interventions. Steph also discussed how staff rarely communicate with her: "….they don't really invite us in….I am in email contact when I need to be, erm, but that's, that's about it really" (1263-1266).

Three participants further noted that staff have not implemented intervention strategies despite being aware of these. For example, Anna discussed how nursery staff failed to implement strategies that had been recommended by a Specialist Teacher whilst her daughter was still attending nursery: "….it was just like the non-direct, kind of just giving her like a summary of what they were going to do, have a visual timetable, all the normal stuff, but I didn't really see it happening…." (1078-1080) and "….they said that they had a board up every day so that she could, if she didn't want to talk, she could put her name up on the board. I went in there, there were no boards up…." (946-954). Steph also reported that staff in her daughter's school, including her class teacher, have not committed to delivering the 'sliding-in' technique despite being advised to use this technique by a Paediatrician.

> "….she (Paediatrician) did write to the school and actually she did say, 'cause at that point he (teacher) was being really rubbish and not engaging with the sliding in at all [frowns]….'I can't tell them that they have to do it, but I can I strongly recommend it' and she did, but that didn't make a difference either [shakes head]" (1314-1323).

This led to the following subordinate themes: 'lack of recognition and understanding', 'lack of collaboration', and 'lack of commitment to intervention'.

Three participants further discussed how they have struggled to access support from services, resulting in the subordinate theme of 'lack of access to support services'. For example, Steph discussed how her daughter had been turned down for support by multiple services due to either not meeting their threshold or the service not offering support for CYP with SM and how she had instead been offered parenting support which she did not feel was helpful:

> "….apparently because she does say some words sometimes she's not severe enough to be seen by a school nurse and what they did was start giving us all these referrals for parenting support and things….it was frustrating 'cause it was like hmm I don't, that's not really what we need" (321-326)

Delia also discussed how she has struggled to access support from a "Paediatric Psychologist" (779) and how staff in her son's school are unsure of where to access additional support from and instead rely on her knowledge: "….they just tell me 'yes this is it unfortunately, we don't know what else to say, er, you know more than we know, this is it, this is it'…." (711-714).

4.3.5. Superordinate Theme 5: Parent Taking on the Role of an Advocate

All but one participant explained that they have had to be proactive in building up an understanding of SM and in seeking relevant support, pushing for others to make referrals or making referrals to services themselves. For example, Delia shared:

> "….whatever I do I have to, er, start it myself. Erm, *I* was the one who as doing the investigation, I was the one who hired a private Speech and Language Therapist….I had to convince the GP to send me to the Paediatrician, erm, so [sigh] no I don't feel I have support. I feel that I have to fight for everything…." (936-942).

Laura also reported "….I literally trawled the internet for weeks sometimes, seeing what help and advice I could get" (958-959). Laura's choice of words here, including the word "trawled", suggests that she has previously spent a significant amount of time looking for support.

The parents further discussed how they have encouraged staff to learn more about SM, for example "I emailed and I said 'I would *really* appreciate if you would do a bit of reading up about it' and gave references…" (Steph, 422-424).

The parents also discussed how they have had to be persistent in requesting staff to implement relevant support and tackle challenges experienced by their child. For example, both Laura and Steph referred to having to repeatedly ask staff to tackle the peer bullying that their children were experiencing and that they reached the point of considering removing their child from the school: "….it got to the point where I told the school 'my daughter's no longer coming in until this is sorted out'" (Laura, 765-766) and "….it did take me saying 'you need to speak to those individuals and tell their parents and if you haven't done it by break time today I'm coming to pick her up'…." (Steph, 238-241).

These findings resulted in the subordinate theme of 'parent taking on the role of an advocate'.

4.3.6. Superordinate Theme 6: Parental Coping Strategies

Three participants explained that they cope with their child's experience of SM by accessing online support groups, including a group for parents and professionals run by the SMiRA charity. The parents noted that the online SMiRA group is particularly helpful in enabling them to gain access to information resources. Delia and Charlotte also discussed how adults with SM often share their experiences within the group which they find helpful in building up their understanding of the phenomenon. For example, Delia reported "I follow the group (SMiRA parent/professional group) on Facebook….I find helpful….especially when people with Selective Mutism give their, give their perspective, I find it very very useful…." (Delia, 891-898), whilst Charlotte reported:

> "….I looked up and, and joined a couple and occasionally I go on there and read things. There are quite a few posts, a lot of them actually from, erm, people that suffer with Selective Mutism and anxiety and stuff….people put recommendations on there, books to read, and things like that, which is really good" (Charlotte, 906-915)

Three participants further reported that they would like to meet up with other parents of children experiencing SM on a face-to-face basis. This seemed to be related to a desire to 'emotionally offload': "….it would be really nice if there was something just where you could go and just talk, yeah offload but may be have people to talk to who kind of knew a bit about it as well" (Steph, 1527-1530).

Moreover, three participants implied that they cope with their child's difficulty talking through simply accepting the phenomenon and tackling challenges as they occur. This is evident in the phrases used by many of the participants, such as "….it is what it is" (Vicky, 1187-1188) and "….learnt to live with it" (Charlotte, 508). Delia also discussed how she tries to "….deal with whatever comes" (984).

Finally, two participants discussed how attending SM training delivered by a SLT has been helpful. For example, Anna shared "____(Name of SLT) was amazing. That whole training I sat nodding all the way through….it was incredible, just everything she (SLT) said I was like 'yes yes', it was a real moment." (250-261). Anna's phrase "a real moment" alongside her reference to nodding throughout the training suggests that the training validated her views and helped her to make sense of her experience. Charlotte also suggested that the training validated her views through sharing: "….the training was just fantastic….just everything slotted into place….everything that they said in the training was yeah, yep that's my child…." (1022-1025). Moreover, one participant referred to wanting support from a 'specialist'. This seemed to be related to the parent's desire to receive advice and guidance around intervention strategies as opposed to being signposted to information resources (which other professionals may have done):

> "Everything else, it's not so much of support, because it's things we, I already know, information you can find on internet. Er, I don't need that, I need something more [emphasis on word] than that, something more advanced….I need to see specialist, I need a Paediatric Psychologist to properly assess him and guide me" (Delia, 569-779)

This resulted in the following subordinate themes: 'social networking', 'acceptance', and 'specialist input'.

4.4. Summary

This chapter has presented the themes arising for each participant's unique experience of understanding and supporting their child with SM, along with the themes that are shared between the participants. The following chapter will explore and discuss the meaning of the findings in relation to the research questions, current literature, and psychological theory. The limitations of the research and the implications for future practice will also be discussed.

Chapter 5: Discussion

5.1 Introduction to Chapter 5

Chapter 4 presented the research findings from the process of IPA within and between participants. This chapter will first discuss the findings in an attempt to answer the four research questions, with links made to the current literature and theoretical framework underpinning this research (outlined in chapter 2). The strengths and limitations of the research, alongside plans to disseminate the findings, are then discussed. Implications for practice and further research and the researcher's reflections are also explored. A conclusion for the entire thesis is then presented.

5.2 Discussion of the Findings in Relation to the Research Questions

5.2.1 What are Parents' Experiences of What may have Led to their Child Presenting with SM?

The theme 'nature and nurture', representing parents' views that SM is related to both biological and environmental factors, helps to answer this question.

5.2.1.1 Nature and Nurture. Four parents perceived genetic factors to have played a role, explaining that their child has appeared anxious from birth. Three parents also noted that there is a close family history of anxiety and other mental health difficulties, such as depression. Two parents discussed how they themselves have struggled with anxiety, whilst one parent discussed how their child's father possibly experienced SM as a child. A familial link is inconsistent with how Cunningham et al. (2004) found no difference in family functioning or maternal mental health between children with and without SM. However, it is consistent with the finding that parents of children with SM scored significantly higher on measures of emotional distress than controls (Alyanak et al., 2013), and how 12% and 33% of parents (out of 27) reported that they had at least

one relative with SM or a social anxiety disorder respectively (Schwartz et al., 2006). Within various case studies, parents have also reported a family history of anxiety (Christon et al., 2012) or that they were timid as children (Albrigsten et al., 2016).

However, three parents noted that their child's personality traits, such as fearfulness, emotional sensitivity, and perfectionism, may have also contributed. This is consistent with how the young person in Christon et al.'s (2012) study was described as a "perfectionistic" (p. 480), avoiding speaking if she felt unable to perform perfectly. Some researchers have also related SM to timidness and introversion, with both traits resulting in behavioural inhibition in unfamiliar situations (Fox et al., 2005). Furthermore, one parent discussed how she believes that bilingualism has played a role, noting that her son initially struggled to distinguish between Greek and English, unlike her daughter who has not experienced SM. This was not explored by the literature in chapter 2, but other research has suggested that bilingual children may indeed be more vulnerable to SM due to concerns about how other people will respond to their limited fluency or accent (Leacox et al., 2016), especially if they are also shy or introverted (Tabors, 1997). This is consistent with how the twins in Albrigsten et al.'s (2016) study stopped talking as a result of peers teasing them about their dialect.

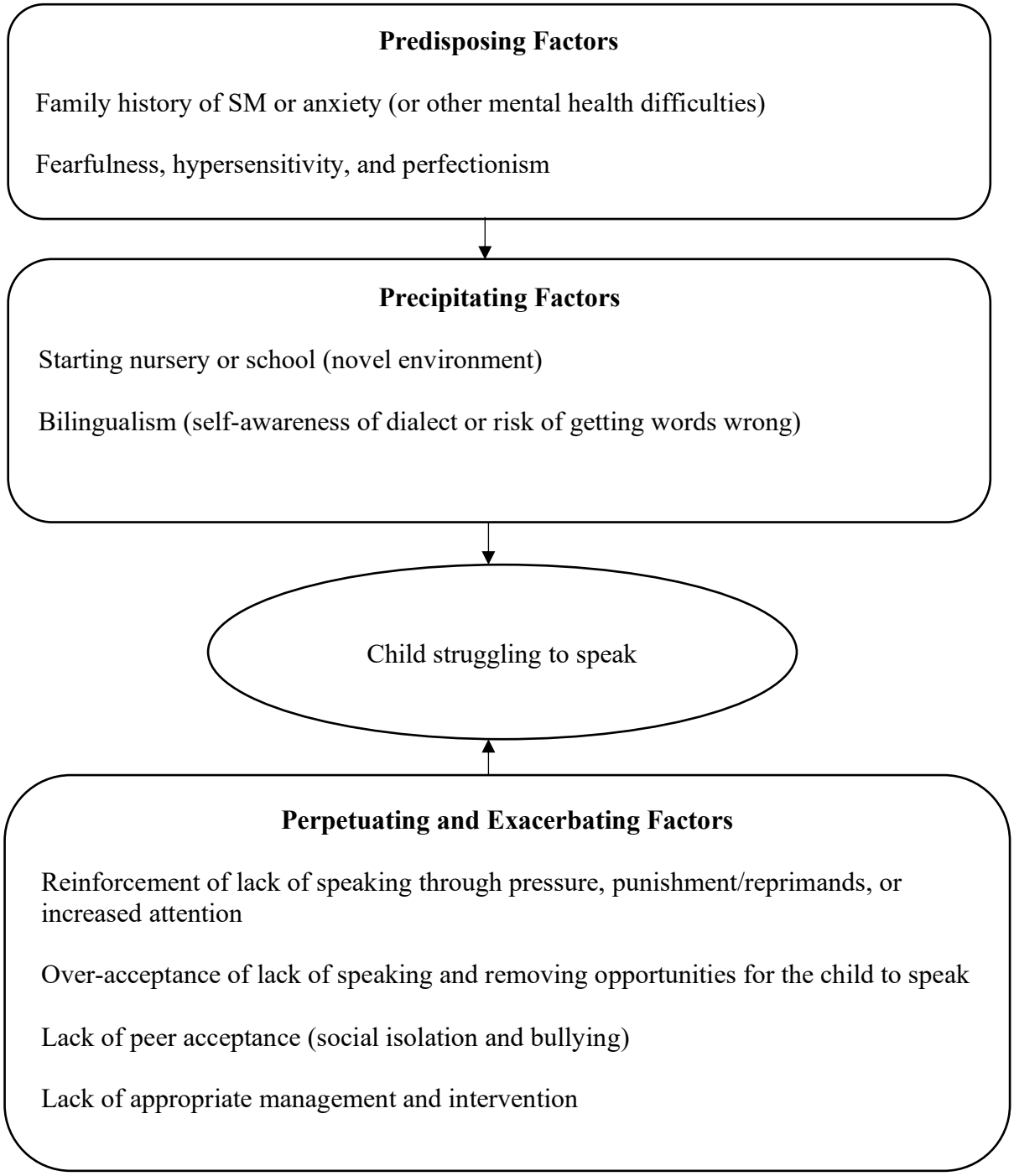
In light of the above findings, three parents concluded that their child's difficulty speaking is due to a combination of biological and environmental factors. The parents also referred to some factors as the 'first' or 'predisposing' factor and others as the 'second' factor, suggesting that they perceived their child to be vulnerable to developing anxiety and that an event in the environment then precipitated (triggered) their difficulty talking. Many parents later noted that the way in which school staff or relatives had responded to their child had also exacerbated their anxiety. This is consistent with how Johnson and Wintgens (2001) have conceptualised SM within a framework of predisposing, precipitating, and perpetuating factors. This framework has been adapted with the experiences of the parents in the current study in mind (Figure 5.1).

An interaction between the child's individual factors and the environment around them, including others' responses, is further consistent with the bioecological systems theory

(Bronfenbrenner & Morris, 1998). As discussed in chapter 2, Bronfenbrenner & Morris (1998) suggest that the child is at the centre of various interconnected systems and that interactions between the child and these systems determines their behaviour.

Figure 5.1

Conceptualisation of SM within a Predisposing, Precipitating, and Perpetuating Framework Based Upon the Parents' Experiences (adapted from Johnson & Wintgens, 2001)



5.2.2 What are Parents' Experiences of the Impact of SM?

The parents discussed how SM has had a detrimental impact on many aspects of their child's life, including their emotional, social, and physical wellbeing and educational experience, and on their own emotional wellbeing and the wellbeing of the whole family.

5.2.2.1 Impact on the Child. All parents reported that SM has reduced their child's confidence and most reported that it has reduced their mood, with their child appearing sad or depressed. Three parents also discussed how it has evoked a high level of distress, for example with their child screaming and crying in the night. These findings corroborate and extend on the finding that children with SM scored significantly higher on measures of internalising difficulties (Alyanak et al., 2013) and how a young person scored within the clinical range on various parent-report measures of wellbeing (Christon et al., 2012). Consistent with the accounts of the parents in Albrigsten et al.'s (2016) study, one parent further discussed how her daughter had previously experienced 'meltdowns' after school, relating this to physical exhaustion in response to containing herself throughout the day. However, parents also related their child's emotionality to difficulties in making friends and accessing learning, suggesting that environmental factors mediate the relationship between SM and poor emotional wellbeing. This is again consistent with the bioecological systems theory (Bronfenbrenner & Morris, 1998).

Four parents reported that SM has acted as a barrier to their child interacting with adults and peers, resulting in a lack of friendships and social isolation. Two parents described how their child 'shuts down' in social situations, freezing on the spot and looking at the floor. This corroborates with the parents' description of how their daughter responded to social situations in Christon et al.'s (2012) study. The parents also noted that this is not a result of their child lacking the motivation or skills to socialise, contradicting the finding that children with SM scored lower on measures of social cooperation (Cunningham et al., 2004). Consistent with the bioecological systems theory (Bronfenbrenner & Morris, 1998), the parents further felt that others had contributed to their child's

withdrawal, for example with staff pressuring them to speak or peers no longer initiating interaction. Consistent with the twins in Albrigsten et al.'s (2016) study, two parents also explained that their child has been bullied by their peers, highlighting the real social vulnerability of these CYP.

Four parents explained that SM has acted as a barrier to their child's learning and academic progress. Three parents explained that their child is performing significantly below age-related expectations, two of whom felt that this did not reflect their child's true ability, suggesting that they have not reached their academic potential. Parents reported that their child particularly struggles with phonics and reading aloud. Parents also reflected on the barriers of struggling to ask for help and concentrate in the face of anxiety. This contradicts the finding of no difference in the academic performance of children with and without SM (Cunningham et al., 2004) but is consistent with other studies (Christon et al., 2012; Albrigsten et al., 2016).

Two parents also discussed how their child is often reluctant to go to school, becoming distressed at drop-off. The fact that the young person in Christon et al.'s (2012) study experienced similar difficulties and then fell into a pattern of school refusal suggests that CYP with SM are at significant risk of disengaging from education. However, for one parent her daughter had recently appeared happier attending school due to making a friend, suggesting that friendships can buffer this challenge.

Consistent with the accounts of the parents in Albrigsten et al.'s (2016) study, three parents explained that SM prevents their child from communicating their basic physical needs, such as when they need the toilet or are in pain, resulting in severe implications. Consistent with the young person's needs in Christon et al.'s (2012) study, parents also reported that their child experiences physical signs of anxiety and that it affects their sleep and appetite. It is helpful here to draw upon Maslow's (1943) hierarchy of needs model (Figure 5.2), which suggests that humans have five areas of need and that one area of need typically needs to be satisfied before another area of need can be fulfilled. The first area of need is 'physiological needs', including the child's ability to eat and drink and go to the toilet, whilst the second area of need is 'safety needs'. This refers to the child's ability to feel safe

and secure. The third and fourth areas of need are then 'love and belonging', the child's ability to form social relationships, and 'esteem', the child's ability to build self-confidence. The final area of need is 'self-actualisation', where the child is able to reach their potential in every aspect of their life.

Figure 5.2

The Hierarchy of Needs Model (Maslow, 1943)

This model helpfully highlights how the difficulty that some CYP with SM have in expressing and meeting their basic physical needs, such as eating and drinking, may contribute to some of their other challenges, including a lack of friendships and confidence and difficulties in reaching their academic potential. However, it is important to note that Maslow (1987) later updated his theory to suggest that the satisfaction of needs is not an "all-or-none" phenomenon (p. 69), meaning that one need does not to be 100 percent satisfied before the next need is met. Research has also criticised the hierarchical nature of the model with discrete areas of need, suggesting that individuals may in fact fulfil their needs in any order and fulfil more than one need at any one time (Wahba & Bridwell, 1976). It is, therefore, important that school staff and professionals take a holistic approach to supporting children with SM, targeting their ability to express and meet their basic physical needs if this is a key challenge for them (for example, with the use of alternative communication strategies) whilst also still targeting their social, emotional, and learning needs.

5.2.2.2 Impact on Parents. Five parents reported that their child's difficulty speaking has had a detrimental impact on their own emotional wellbeing. Similar to the parents in Christon et al.'s (2012) and Albrigsten et al.'s (2016) studies, parents reported feeling stressed, worried, frustrated, helpless, and depressed. One parent had also experienced a mental breakdown.

Parents related such emotional experiences to continuously witnessing their child's distress and to concerns about the future. This is consistent with how parents of children with an anxiety disorder initially experienced their child's distress as their own (Pishva, 2017). One parent also reflected on how she feels like a 'bad parent' due to having to send her daughter into situations that evoke anxiety, including school. This seemed to reflect a sense of dissonance between her natural parenting instinct to protect her child and the need to give her child an education. This is similar to how parents experienced dissonance between implementing CBT strategies and immediately removing their child's distress by removing them from the situation (Pishva, 2017).

Furthermore, parents related feelings of stress and frustration to not knowing how to support their child and struggling to access support in nursery or school and from external professionals. This is consistent with how the transactional stress and coping model (Lazarus & Folkman, 1984) suggests that stress is caused by the perception of threat combined with a perceived lack of resources to cope.

One parent also related her sense of frustration and loneliness to how different her parenting experience is to what she expected and to other parents' experiences, indicating a possible sense of loss. A sense of loss and grief has repeatedly been identified in the literature for parents in response to their child receiving a diagnosis of ASD (Fernańdez-Alcántara et al., 2016; Wayment & Brookshire, 2017; Young et al, 2020). However, it has not previously been identified in the SM literature, meaning that this is a relatively novel finding.

Moreover, parents often appeared to be a source of safety and comfort for their child, with their child seeking close proximity, particularly in social situations. This is consistent with Pishva's (2017) findings and Bowlby's (1973) idea of a 'secure base', where children are able to explore the

environment with the knowledge that they can return to the adult for comfort when needed. However, being a source of safety also likely contributes to the poor wellbeing of parents as the parents in the current study noted that they lack freedom and time for self-care and have had to put their own aspirations on hold.

Overall these experiences, alongside how two parents reflected on how their own anxiety can exacerbate their child's anxiety, support the idea of bi-directional interactions between the child and their parent (Bronfenbrenner & Morris, 1998).

5.2.2.3 Impact on the Wider Family. Two parents reported that their child's difficulty speaking has at times affected the whole family unit, including siblings. One parent reflected on how the atmosphere at home has been highly fraught, whilst another reflected on how her son's younger sister absorbs his anxiety and copies unhelpful behaviours. This is consistent with how the parents in Albrigsten et al.'s (2016) study reported that the family home became filled with "worries and blame" (p. 7) and how their daughter was affected, developing enuresis. One parent also went on to discuss how it affects family outings and places a strain on her relationship with her partner. These findings are again explained well by the bioecological systems theory (Bronfenbrenner & Morris, 1998), where the individual child continuously interacts with their immediate environment, including the family system.

5.2.3 What are Parents' Experiences of Support?

Parents' experience of accessing support for their child differed significantly and largely depended on what resources were available within the educational setting and LA. This question will, therefore, be answered by first exploring support that parents have accessed and found effective in helping their child to combat SM, and then exploring the challenges that parents have faced in accessing support and how parents often take on the role of an advocate.

5.2.3.1 Available and Helpful Sources of Support. Four parents reflected on how nursery and school staff have made adaptations to the setting and routines, such as avoiding big group activities and giving their child alternative ways to communicate, and how this has reduced their child's anxiety and promoted their inclusion. The powerful impact of such accommodation is also reflected in the literature, for example only those pre-schoolers where staff had made various adaptations had overcome SM at a one-year follow-up (Omdal, 2008).

Three parents further felt that a dedicated member of staff, someone who consistently looks out for and checks in with their child, has been helpful. The parents noted that their child has built up a trusting relationship with this adult, which has then enabled them to speak and communicate their basic needs. One parent also reflected on how the adult is a source of security, enabling her daughter to go into nursery without becoming distressed. This suggests that the member of staff can act as a 'secure base' (discussed in section 5.2.2.2), which may then buffer many of the implications of SM. The importance of a secure relationship with an adult is a novel contribution to the SM literature but has previously been explored by a wealth of research within the field of attachment (Bowlby, 1973; Waters & Cummings, 2000; Golding, 2003; Vandesande et al., 2019). One parent further noted that such support has ensured the continued delivery of interventions, which is hugely important as tackling SM in the environment in which it occurs leads to more successful outcomes (Christon et al., 2012; Bergman et al., 2013).

Three parents also reflected on how staff have worked in partnership with themselves, for example arranging joint problem-solving meetings, and how this has resulted in staff developing a greater understanding of their child's needs and necessary support. This is consistent with Christon et al.'s (2012) conclusion that the process of the parents and teacher working together to implement exposure-based activities played a key role in helping a young person to overcome SM.

The power of such support is understood with reference to the bioecological systems theory (Bronfenbrenner & Morris, 1998). The process of staff making adaptations to the educational setting and offering a 'secure base' (at the 'microsystemic' level) directly influences the child's experience

and perceptions of school, helping them to perceive it as a safe and pleasant environment. This then in turn reduces the child's anxiety. The process of staff and parents working together (in the 'mesosystem') also contributes to how knowledgeable the staff are, which then enables them to implement the right support.

5.2.3.2 Challenges in Accessing Support. In contrast to the above findings, over half of the parents reported that nursery and school staff, and even professionals, had demonstrated a lack of awareness and understanding of SM. Parents reflected on how this had resulted in delays to staff recognising and notifying them of their child's difficulty talking and in their concerns not being taken seriously, delaying assessment and intervention. This corroborates with how parents reported that it took an average of 11.5 months for their child's PCP to take their concerns seriously (Schwartz et al., 2006), and how one child was not assessed until the age of 8-years-old despite experiencing SM since reception (Fisak et al., 2006). Two parents further explained that their child has been incorrectly perceived as defiant, resulting in staff and relatives exacerbating their difficulty speaking, for example by providing reprimands. One parent also discussed how their child has gone 'under the radar' due to a lack of disruptive behaviour. This is consistent with how a parent in Omdal's (2008) study explained that staff had not implemented support due to a lack of behavioural difficulties.

An additional challenge for three parents was staff failing to make adaptations and implement support strategies, such as the use of visuals, even when advised to by external professionals. Similar challenges are clear in the literature, for example with staff struggling to implement CBT (Pishva, 2017) or behavioural techniques (Fisak et al, 2006). Parents also reflected on how a lack of adaptation had prevented their child from participating in activities, indicating a lack of social inclusion. This is of significant concern as excluding a child from social activities can result in SM becoming part of their social identity, making it even harder to overcome (Omdal, 2008). One parent related this challenge to a lack of understanding of SM, whilst two parents felt that staff wanted to help but lacked the resources to do so.

A further key challenge for three parents was a lack of opportunity to work in collaboration with staff. Two parents noted that they are rarely invited to meetings, whilst another noted that staff in her daughter's previous nursery were reluctant to take her advice on board. The detrimental impact this can have on the progress of CYP overcoming SM is clear in Omdal's (2008) study, with children whose parents reported difficulties in working with their teacher still experiencing SM at a one-year follow-up.

Moreover, half of the parents had struggled to access specialist support services, such as their local Speech and Language Therapy Service and CAMHS, noting that they had made numerous referrals which had all been rejected or that they were unaware of what services could help. As a result, the parents felt lost and uncertain about what next steps to take and some had resorted to private sources of support.

The impact of such challenges in accessing support is again best understood with reference to the bioecological systems theory (Bronfenbrenner & Morris, 1998). A lack of understanding by adults in the child's immediate environment ('microsystem'), including school staff, results in them building up inaccurate perceptions of the child, which then leads to them interacting with the child in a way that reinforces their anxiety. A lack of collaboration between the home and school systems ('mesosystem') also contributes to a lack of support as staff are not able to learn from the parents or draw on the parents as a resource in delivering interventions. Furthermore, a lack of professional input (at the 'exosystemic' level) may feed into the tension between the home and school due to both staff and parents feeling unsure about how to support the child. Finally, the lack of available support services is likely related to wider societal factors, such as commissioners failing to allocate funding.

5.2.3.3 The Importance of Advocacy. All but one of the parents appeared to take on the role of an advocate for their child, reporting that they have had to persistently fight and push for their child to be accurately understood and adequately supported. For example, by actively sharing information resources with relatives and staff, making and chasing referrals, raising concerns with staff and

escalating concerns when needed, and co-delivering intervention programmes in school. One parent referred to her self-knowledge as 'ammunition', helping her to know what to fight for. Most of the parents also felt that without their input their child would be in a worst place, suggesting that advocacy is a necessity. This is consistent with how parents adopted the role of an advocate following their training in CBT, actively encouraging school staff to embed strategies (Pishva, 2017). A wealth of research has demonstrated how parents of children with SEND often taken on the role of an advocate for their child (Wright & Taylor, 2014; Boshoff et al., 2016). However, this role has not previously been addressed by research within the field of SM, making this a relatively novel finding.

5.2.4 What are Parents' Experiences of Coping with their Child's SM?

As discussed in section 5.2.2.2, bringing up a child with SM can be an emotionally challenging experience. The current research revealed three primary factors that help parents to maintain their own wellbeing, although whether parents had access to two resources again depended on where they lived. These findings are unique as although much research has been conducted into how the parents of children with learning disabilities (Al-Yagon, 2015; Beighton & Wills, 2017) and ASD cope with their child's needs (Gray, 2006; Shilubane & Mazibuko, 2020), no studies have previously focused on this topic within the field of SM.

5.2.4.1 Specialist Input. Two parents reported that they have accessed SM training and ongoing advice from a SLT specialising in SM through their local NHS Speech and Language Therapy Service and that this has been a source of emotional and practical support. For example, noting that the training validated their views, helped them to better understand their child, and increased their confidence in delivering interventions. One parent also discussed how the SLT had provided advice on how to encourage her daughter's nursery to be more supportive. Two additional parents further expressed a desire to receive such professional input in order to know what next steps to take. Access to a professional who specifically specialises in SM also seemed important with one

parent noting that they will be better placed to help. The power of supportive professionals is evident in Albrigsten et al.'s (2016), for example with the twins' father reporting that feeling heard and validated was the most important element of support he received at the family unit.

5.2.4.2 Social Networking. Networking with other parents of children with SM was a prominent coping mechanism with three parents explaining that they had joined various online SM support groups and that this had enabled them to access information resources and learn from other parents. Three parents also explained that they would like to attend a face-to-face SM parent group, although only one parent new of a group in their local area. This seemed to reflect a yearning to problem solve but also emotionally offload and share the strain with those who can fully appreciate and understand their experience. One parent specifically referred to wanting to hear another parent say "I know". The importance of social networking for parents of children with SM has not previously been explored. However, there is a wealth of literature highlighting the benefits of support groups for parents of children with ASD and learning disabilities, for example offering a sense of belonging and emotional containment and giving parents the knowledge and courage to 'fight' for support (Solomon et al., 2001; Law et al., 2002; Kingsnorth et al., 2011).

5.2.4.3 Acceptance. The final key coping mechanism was 'acceptance', accepting their child for who they are and SM for what it is rather than constantly fighting the phenomenon or ruminating. Parents also acknowledged that they can only tackle one challenge at a time and do their best. One parent further referred to accepting that her daughter is still 'in there' and that she will eventually overcome the phenomenon, but that this will take time and patience. Adopting such a resilient mindset seems to help parents to remain proactive whilst keeping their emotions in check, perhaps preventing them from feeling overwhelmed.

5.2.4.4 Emotion-Focused Versus Problem-Focused Coping. Overall, parents adopt various 'problem-focused' and 'emotion-focused' coping mechanisms (Lazarus and Folkman, 1984). Access to specialist support appears to be a problem-focused mechanism as it provides parents with the knowledge, skills, and confidence to deliver intervention approaches, whilst social networking and acceptance appear to be both emotion- and problem-focused mechanisms. Liaising with other parents provides parents with ideas on how to tackle challenges associated with SM and also provides a 'safe space' for them to 'emotionally offload'. Moreover, acceptance enables parents to be pragmatic, tackling challenges as they occur, and to avoid overthinking which may result in their emotions escalating. It is likely that these mechanisms reduce parents' perceptions of the threat of SM and buffer stress.

5.3 Critique of the Research

As intended, the research has provided a deeper understanding of what may lead to the onset of SM, the impact of SM, what support is available and effective, and how parents cope and maintain their own wellbeing. This has the potential to improve the understanding and practice of nursery and school staff and professionals. The parents also appeared grateful and relieved to have shared their views, thanking the researcher and acknowledging that things are more likely to change with their input, indicating a sense of psychological empowerment (Zimmerman, 1990). However, there are numerous limitations associated with the findings, including how the research took place within the context of Covid-19 where various national lockdowns (including school closures) were enforced. This had a significant impact on the research process and likely affected the findings. This limitation, alongside other key limitations, are discussed in detail below.

5.3.1 Procedure

As discussed in section 3.8.1, the researcher did not conduct a pilot study. Whilst this did not feel necessary during the planning stage, is possible that a pilot study may have highlighted additional

informative questions to ask during the interviews and highlighted some of the challenges noted above, giving the researcher time to consider adaptations to the study to overcome such challenges. This would have further empowered the parents to share their experiences, increasing the credibility the findings.

5.3.2 Sampling

Owing to the qualitative design, only a small number of parents were recruited. To ensure homogeneity, required for the cross-case analysis stage of IPA, the parents also had to meet a number of inclusion criteria. For example, their child had to be attending (or have recently attended) nursery or primary school and have a confirmed diagnosis of SM. Although not a criterion, the sample further only consisted of mothers, most of whom appeared highly educated and had accessed independent services, indicating some access to financial resources. This limits the extent to which the findings can be generalised to other parents of CYP with SM, in particular parents of CYP in secondary school where routines and expectations differ significantly to primary school, resulting in potential differences in their experience of the impact of SM and support. Fathers and parents from more deprived backgrounds may also have slightly different experiences. As fathers are still generally less involved in childcare than mothers (Chesley & Flood, 2017) it may be, for example, that they experience different implications of SM. Differences in how men and women respond to mental health difficulties, with men finding it harder to openly discuss mental health (Brown et al., 2019), may also mean that fathers develop different coping mechanisms. Fathers may, for example, find networking with other parents less helpful than mothers. Moreover, those parents who did not meet the criteria due to a lack of a confirmed diagnosis reported challenges in accessing a diagnosis, immediately indicating a difference in their experience of recognition and support to the current sample. The findings, therefore, represent just one sub-group of parents.

5.3.3 Data Gathering and Findings

Semi-structured interviews required parents to respond to questions 'on the spot' (with little thinking time) and it is possible that this, alongside the remote nature of the interviews (due to Covid-19), felt too threatening for some parents and prevented them from participating in the research. This is an important consideration given that the findings suggest that anxiety and SM can run in families, meaning that parents may too experience anxiety. Despite the parents who did participate appearing to talk in an open manner, it is also possible that they at times felt inhibited by having to talk through a microphone, especially when asked emotive questions, and shared less information than they would have done in person. This reduces the validity of the data.

Moreover, as a result of school closures most of the parents' children were at home during the interview. This resulted in inevitable disruptions, which may have made it difficult for parents to fully immerse themselves into the interview and share all of the information that they wished to share, again limiting the validity of the data.

The Covid-19 pandemic had also appeared to affect the parents' experiences of SM, with the parents noting various positive and negative implications. Many parents reported that their child had appeared more relaxed and happier since being educated at home, but that they were concerned about how their child would cope once they returned to school and that they may regress. It is possible that this, alongside the potential direct impact of the pandemic on the parents, had heightened the stress and anxiety reported by the parents and pushed their other concerns and issues to the side. A heightened emotional state seems likely given that there has been a significant increase in parental stress over the course of the pandemic (Brown et al., 2020; Pierce et al., 2020). This brings into question the generalisability of the findings outside of the pandemic.

5.5 Plans for Dissemination

Dissemination of the findings to the participants and wider community is vital in ensuring that the parents feel empowered and that their experiences inform practice.

5.5.1 Dissemination to Participants

At the end of the interviews the parents were told that they would receive a summary of the research findings with a link to the whole thesis document on the British Library E-Theses Online Service database. The summary and link will also be shared with those parents who volunteered to participate in the research but did not meet the inclusion criteria.

5.5.1 Dissemination to the Wider Community

The researcher plans to share the findings with other parents of CYP with SM, staff in early years settings and schools, and with educational and health professionals, as widely as possible.

At a local level, the researcher will share a summary of their findings with EPs within the EPS where they are currently completing a placement and EPs within an EPS they are due to join once qualified. The researcher will also present the findings to EPs within their current EPS at a service day in July 2021. The researcher will look to do this in collaboration with the participants, inviting them to co-present. The researcher will further share the findings summary with the local Speech and Language Therapy Service and create a flyer, outlining key findings and recommendations for practice, to share with early years settings and schools. Nursery and school staff will also be asked to share the flyer with parents of CYP with SM. Furthermore, the researcher will draw upon the findings when delivering training on SM to schools and when consulting with staff and parents.

At a national level, the researcher will present the findings at a yearly SM conference organised by SMiRA, attended by parents and professionals. The researcher will also share their summary document with EPs across the country through EPNET (an online forum) and look to publish the findings to ensure access by the wider academic community.

5.6 Implications for Practice

The findings highlight several implications and recommendations for nursery and school staff, health and educational professionals, in particular EPs, and parents to ensure that CYP experiencing SM are accurately understood and adequately supported.

5.6.1 Implications for Nursery and School Staff

A critical first step is for all teaching and non-teaching staff in early years and school settings to build up their awareness and understanding of SM, for example through accessing the SMiRA website and training. A potential barrier to this is the often limited resources in schools, however this barrier can be overcome by one staff member developing their knowledge and then cascading their knowledge to others.

Furthermore, when staff suspect that a child may be experiencing SM, they should notify their parents as soon as possible and closely monitor the child, ensuring that they do not slip 'under the radar'. Staff should also make immediate adaptations to the environment and their interactions with the child to reduce their anxiety. This should include giving the child alternative ways to communicate their needs and desires. Staff should then look for ways to target the child's speaking behaviour, seeking advice from, or making referrals to, external support services if needed. Such support must be sought in a timely fashion.

In addition, staff should remain aware of the challenges associated with SM, such as poor self-confidence and a difficulty establishing friendships, and ensure that they target these challenges alongside the child's difficulty speaking. For example, to help the child to make friends and develop a greater sense of social belonging, staff should include them in all social activities, making adaptations to allow their participation, and educate their peers about SM.

Staff must also ensure that the child has access to one consistent member of staff who can build up a trusting relationship with them and act as their 'secure base'. This adult should check in

with the child throughout the day to demonstrate that they are 'holding them' in mind and are there for reassurance when needed.

Finally, it is vital that staff work in collaboration with parents, seeking their views and expertise and involving them in planning, implementing, and reviewing interventions, in order to promote the best outcomes for the child. Staff should also check in with parents about their emotional wellbeing to ensure that they are getting the support that they need and, if not, signpost them to relevant services.

5.6.2 Implications for EPs

Similar to school staff, a vital starting point is for EPs to develop their awareness and understanding of SM, for example through attending conferences and training. Further implications are discussed in terms of the EPs role in supporting pupils, staff, and parents, and in working with other professionals.

5.6.2.1 Supporting Individual Pupils. When asked to assess a child with suspected SM, EPs should first find out how the child can communicate and use this information to identify assessment tools that the child will be able to access. EPs will need to be creative, drawing upon resources such as questionnaires and visuals. Then when meeting the child, EPs should reassure the child that they do not expect them to talk and take some time to build rapport with them to help them to relax. EPs must also ensure that they not only gather information about the child's speaking behaviour but also the implications of this, for example on their social and emotional wellbeing, as this will inform all necessary interventions.

Moreover, EPs are well placed to deliver intervention support, as they have a range of therapeutic skills and knowledge of approaches to help CYP to manage anxiety, such as a Cognitive Behavioural Approach. EPs also have the skills to deliver interventions that directly target speaking

behaviour, including the sliding-in technique. However, due to their often limited time in schools, EPs may be better placed to upskill and supervise staff in delivering such interventions.

5.6.2.2 Supporting School Staff. EPs must promote a greater awareness and understanding of SM in schools by providing psychoeducation, signposting staff to information resources, and sensitively challenging misconceptions in consultations with staff. EPs should also deliver training to staff, focusing on what SM is, necessary adaptations to the school environment, and appropriate intervention techniques.

EPs must also remain mindful of the risk of children experiencing SM going 'under the radar' and help staff to recognise when a child may be experiencing SM to promote early intervention. For example, by asking exploratory questions whenever a member of staff refers to a child as appearing anxious, shy, or withdrawn, or struggling to develop their speech.

EPs should further help staff to understand the importance of a child with SM having access to a consistent member of staff who they can form a secure attachment with. EPs can also support the key adult in building up their relationship with the child, for example by coaching them in the principles of attunement (Kennedy & Landor, 2015) and through Video Interaction Guidance. This would involve showing the adult clips of them interacting with the child to identify moments of exception, where the child is able to talk, to help them to extend on their attuned interactions with the child (Kennedy et al., 2011).

5.6.2.3 Supporting Parents. EPs must remain mindful of how emotionally demanding the phenomenon of SM can be for parents and provide a 'safe space' for parents to share their worries and frustrations to ensure that they feel heard and validated. EPs should also help parents to identify sources of support for themselves. Given that social networking is a key coping mechanism for parents, EPs should help to set up and facilitate parent support groups.

5.6.2.4 Multi-Agency Working. It is vital that EPs understand what other services and professionals in their LA support CYP with SM and work in collaboration with them, making referrals or signposting school staff and parents to them when needed and seeking opportunities to engage in joint problem solving. This is particularly important for EPs who feel less confident in supporting CYP with SM, as EPs must only work within their limits of competence (BPS Code of Ethics and Conduct, 2018).

5.6.3 Implications for Other Professionals

Health and social care professionals, including SLTs, CAMH Practitioners, Paediatricians, GPs, and Social Workers, need to ensure that they too have an accurate understanding of SM. Regardless of whether they are commissioned to work with CYP with SM, professionals must also take parents' concerns seriously and act upon these, referring CYP to services who can offer assessment and support if they are unable to. When there are no such services, professionals should make this known to commissioners and work with them to set up a SM care pathway.

5.6.4 Implications for Parents

It is important for parents to be aware that staff in their child's educational setting may initially lack an understanding of SM and that they can play a key role in helping them to develop their understanding, for example through sharing their own knowledge of SM and the impact of this on their child and information resources that they have found helpful. However, the researcher acknowledges that this may not be possible for all parents, for example due to other competing demands, a lack of support in helping them to understand the phenomenon themselves, or a lack of confidence in sharing their knowledge with staff. The researcher also believes that such a responsibility to educate school staff should sit with professionals, such as EPs, as opposed to parents.

Parents should also work in partnership with staff to identify, plan, and implement appropriate adaptations and intervention programmes to ensure an effective and consistent approach between the school and home setting.

In addition, parents should request that staff remain in consistent contact with them to keep them up-to-date about their child's progress, perhaps suggesting the use of a home-school communication book or requesting regular meetings. If parents feel that their child's difficulty talking is failing to reduce over time they should discuss this with staff and request that advice is sought from external professionals. In light of any disagreement, parents may find it helpful to contact their local SEND Information, Advice, and Support Service for ideas on how to seek resolution with the school or access support services through alternative means.

Finally, parents should remain aware of the potential impact of supporting a child with SM on their own emotional wellbeing and identify and utilise coping strategies, such as taking time out for themselves. This will ensure that the parents have the capacity to continue to advocate for their child.

5.7 Implications for Further Research

Based upon the limitations of this study (discussed in section 5.3), similar research should be conducted with a larger sample of parents from a more diverse range of backgrounds, including parents from a lower socioeconomic background and parents of CYP in secondary school and post-16 settings. Researchers should also seek the views of fathers and other relatives, including siblings. This is likely to shed even further light on the support that CYP with SM and their families require.

Given that the current study touched on many themes but only at an initial exploratory level, it would also be helpful for research to examine these themes in greater detail. This is especially important with those themes that have made a novel contribution to the SM literature, including parental coping mechanisms.

Research should further explore the impact of the Covid-19 pandemic on children with SM and their parents. This seems particularly important as the parents in the current study referred to some implications of the pandemic (discussed in section 5.3.3). Due to the interviews taking place at the start of the pandemic, it is also possible that the parents may have not yet realised or experienced the full impact of the pandemic (and potential necessary adaptations to support) at this time. The pandemic has persisted over the last 12 months, resulting in multiple national lockdowns and school closures, and is still ongoing, possibly leading to more significant implications for parents of children with SM.

In addition, as the current study explored parents' experiences of support in quite a broad sense, further qualitative research needs to be conducted into parents' experiences of specific intervention programmes and techniques, such as the sliding-in technique.

Owing to the continued marginalisation of the SM community, researchers should also consider adopting a participatory research design where parents are involved in designing the research questions and analysing the themes (Robson & McCartan, 2016). This will further empower the parents to contribute to positive change.

Finally, it would be helpful for research to gather the insider views and experiences of other key stakeholders, including school staff and EPs and the CYP themselves. Given that CYP with SM are likely to struggle with face-to-face interviews alternative ways of accessing their voice should be considered, such as instant messaging, writing, and drawing.

5.8 Reflections and Reflexivity

Within this section the researcher reflects on possible sources of bias, including their position as someone who has experienced SM and as a professional, and their key learning. These reflections have been written in first-person due to their personal nature.

5.8.1 Researcher Bias

In light of the qualitative design of this research and my critical realist epistemological position, including my belief that individuals make their own subjective interpretations of reality (Robson & McCartan, 2016) and that knowledge is value-laden (Kwan & Tsang, 2001), I make no claim that the research is objective. My experiences, thoughts, feelings, values, and assumptions undoubtedly played a role in how I approached the research. However, I attempted to minimise such bias by acknowledging and processing my views away from the participants, for example through maintaining a research diary, and completing member checks with the participants and my research supervisor.

5.8.1.1 Researcher's Positioning. As discussed in chapter 1, I am a white, middle-class, female, 28-year-old TEP completing a placement in a large LA, and my interest in SM stems from my own childhood experience of SM, core values, and experience of supporting CYP with SM as a TEP.

I was 4-years-old and had just started school when I first experienced SM. The response and support I received from staff was poor, with teachers pressuring me to speak or excluding me from activities, delaying my ability to overcome the phenomenon. Through working with a child with SM as a TEP, I also learnt that a lack of understanding and support is still an ongoing issue. It is possible that these negative experiences influenced the questions I asked in my research and how I interpreted the findings. The parents' experiences also resonated with my own and sometimes evoked strong emotions, which the parents may have picked up on.

Moreover, I am aware that my role as a professional and my job title, in particular the word 'psychologist', may be associated with power and authority. Most of the parents also had very little awareness of the role of the EP and had previously struggled to get their views across to professionals, which may have resulted in intimidation. As the researcher, I further took control in setting up each interview and in starting and ending the recording, which may have also contributed to the possible

intimidation experienced by the parents. I tried to overcome any perceived power imbalances by using accessible and non-judgemental language, making it clear to the parents that they could finish the interview at any point, and drawing upon the principles of attunement (Kennedy & Landor, 2015) to demonstrate active listening. However, the parents may have still felt unable to share certain information.

5.8.1.2 Key Learning

I have enjoyed every aspect of my research journey and found it a highly rewarding process. The research has undoubtedly increased my understanding of SM, including the implications, necessary support in school, and intervention strategies, including 'sliding-in'. I feel much more equipped in supporting CYP with SM myself and in supporting school staff and parents to help these CYP.

It was also a privilege to step into the parents' worlds and I learnt the real value of doing so in not only learning more about SM but also in empowering parents to contribute towards social change. The interviews also appeared to be a cathartic process for the parents, allowing them to process and make sense of their experiences and 'emotionally offload'. The interview may have, therefore, been a source of support in itself. Based upon this experience, I would definitely consider adopting a qualitative emancipatory research design with future projects. As an EP I will also remain mindful of the power of giving parents a 'safe space' to share their views and feelings and offer every parent this opportunity.

Furthermore, interviewing parents about sensitive issues, including their own emotional wellbeing, and then writing these up in a sensitive and accessible manner, has undoubtedly enhanced my rapport building and verbal and written communication skills, which I will continue to draw upon as an EP.

Finally, I found my research journey highly demanding, at times feeling stressed and doubtful of my ability. However, I identified various helpful coping mechanisms, such as breaking my project

down into small steps, sticking to an organised schedule, and ensuring time for self-care, which I believe will stay with me and promote my wellbeing as an EP.

5.8 Final Conclusions

The aim of this research was to explore the lived experiences of parents' understanding and supporting their child with SM due to a lack of research in this area. This included parents' experiences of the cause and impact of SM, access to support and what support has been most helpful, particularly in their child's educational setting, and how they have coped and maintained their own emotional wellbeing. It was hoped that this would increase the insight of school staff and professionals and result in earlier recognition and more effective support. A total of six parents were interviewed.

The parents experienced SM as a complex phenomenon, resulting from a combination of biological and environmental factors, including genetics (related to a close family history of anxiety), personality traits, and bilingualism. Parents also felt that the response of others, including relatives and school staff, had exacerbated their child's anxiety. Parents hypothesised that biological factors predisposed their child to anxiety and that environmental factors precipitated their difficulty talking.

The parents experience of the impact of SM on their child was extensive. Parents noted a detrimental impact on their emotional wellbeing and ability to make and maintain friendships, access learning and make academic progress, and express and meet their basic physical needs. Some children had also been bullied and were reluctant to attend school. The parents further reported a detrimental impact on their own emotional wellbeing. This was related to witnessing their child's distress, a lack of time and space for self-care due to being their child's 'secure base' (or 'safety blanket'), and difficulties in accessing support and advice. For some, there had also been a detrimental impact on the wider family, including siblings, indicating the need for support at an individual and wider systemic level.

The support that parents had experienced within and outside of their child's educational setting greatly differed and seemed dependent on where they lived and available resources, indicating a real inequality in provision.

Support that some parents had accessed and found helpful included staff making adaptations to reduce pressure on their child to speak and promote their social inclusion, and their child having access to one consistent member of staff who they could build up a trusting relationship with. This then allowed the staff member to become a 'secure base' for their child. Relationships with peers and peer acceptance, alongside the process of parents and staff working together to problem solve, was also helpful.

In contrast, many parents reported that nursery and school staff and professionals had demonstrated a lack of understanding of SM, resulting in delays in recognition and intervention. Parents also noted that staff had struggled to make adaptations and implement interventions despite professional guidance due to a continued lack of understanding or lack of resources. Additional barriers to support included difficulties in working in collaboration with staff and in accessing input from specialist support services.

The majority of parents adopted the role of an advocate, fighting and pushing for others to accurately understand and adequately support their child. This appeared to be an exhausting and emotionally demanding role. Despite this role and the negative implications of SM, parents appeared highly resilient, utilising various coping mechanisms, such as networking with other parents of CYP with SM. However, whether such sources of support were available again depended on where the parents lived, indicating a 'postcode lottery'.

The findings highlight various implications for the practice of school staff and professionals and also parents. A primary implication for staff and professionals is the need to build up a greater awareness and understanding of SM, whilst a primary implication for parents is to continue to be proactive in sharing their knowledge of SM with staff to contribute to their understanding (if they are in a position to do so). The role of the EP is also constructed as being flexible and person-centred in

their approach to assessment, providing therapeutic input, and helping school staff to develop their knowledge and implement appropriate support through consultation, training, supervision, and sharing psychoeducation resources. EPs should further support the wellbeing of parents through providing them with a 'safe space' to 'emotionally offload' and establishing parent support groups. EPs must also work in collaboration with other support agencies.

Through active dissemination, the findings have the potential to increase the understanding of SM by staff in early years and school settings and health, educational, and social care professionals. It is hoped that this will result in earlier recognition and earlier and more effective intervention and help staff and professionals to feel more competent in this area. Over time this will hopefully reduce inequalities in the provision available for CYP with SM and their families.

The researcher is eternally grateful for all of the parents that gave up their time to take part in this study. It is hoped that sharing your story was an empowering experience that will go on to inform practice to enable all CYP with SM to reach their potential and live fulfilled and happy lives.

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Appendices

Appendix A: Stage by Stage Process of the Retrieval and Inclusion and Exclusion of Papers

Figure A1

Literature Search Process One (Using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA] Flow Diagram [Moher et al., 2009])

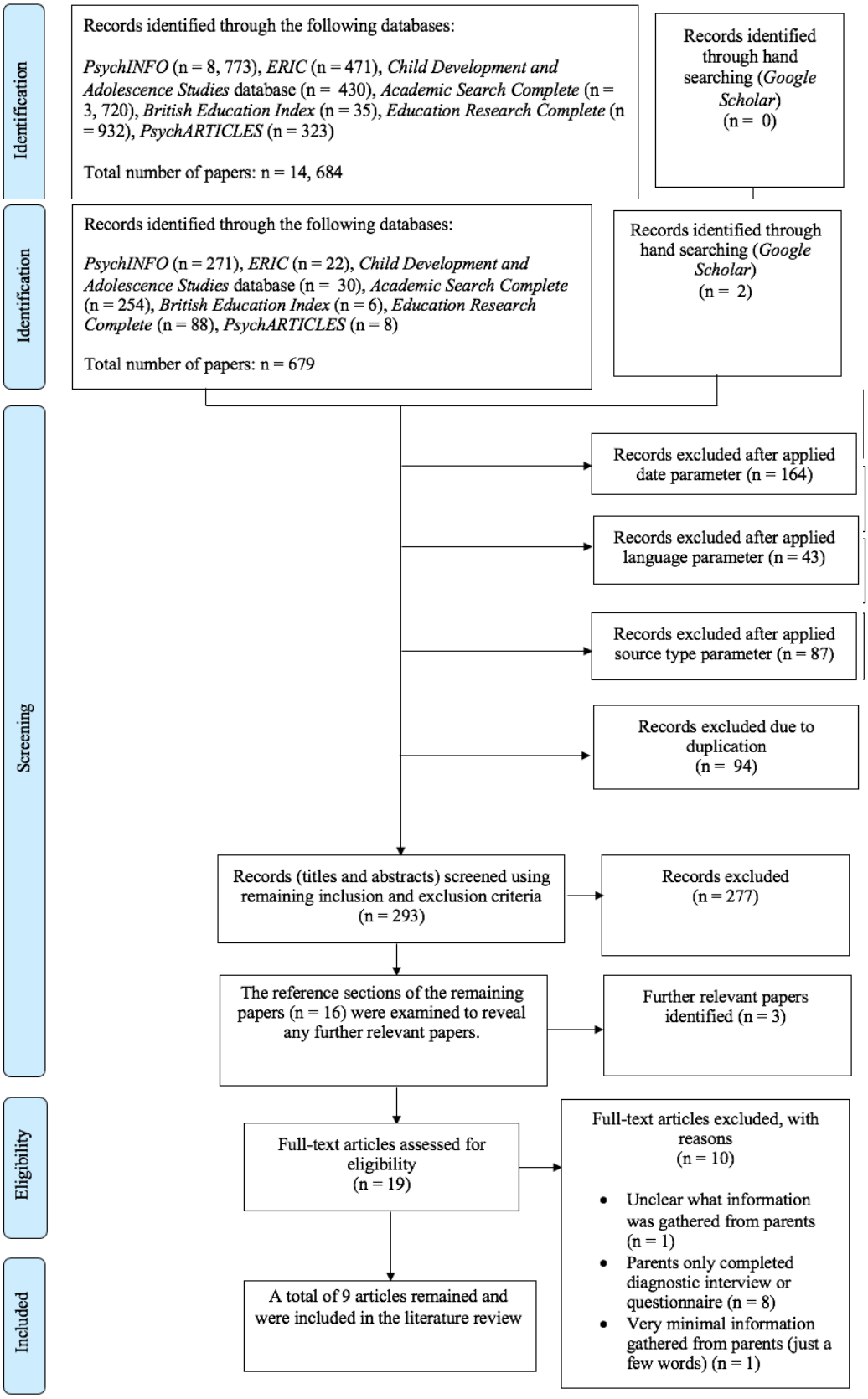


Figure A2

Literature Search Process Two (Using a PRISMA Flow Diagram [Moher et al., 2009])

Appendix B: Table Outlining the Previous Literature

Table 1B

Summary of Each Previous Research Study

Author	Location	Theoretical Orientation	Sample, Design, and Method	Key findings	Critique
Schwartz, Freedy, & Sheridan (2006)	USA	Not clear – briefly covers behavioural interventions and pharmaceutical interventions, consistent with a biological theory (i.e. medication)	*Sample:* • Parents of 33 children (24 females, mean age of 7.9-years-old) *Design:* • Quantitative *Method:* • Parents completed a structured 39-item survey • Statistical analysis	• Parents recognised child's difficulty with talking at an early age, but then struggled to access recognition from medical professionals and appropriate assessment services • Majority of parents found medical professionals to be unhelpful	*Strengths:* • Relatively large sample size – promotes external validity • Basic demographic information provided – promotes generalisability *Limitations:* • High chance of sampling bias (parents had already attended a clinic or were already members of a SM parent support group) – limits internal validity • Lack of qualitative data – limits internal validity

					• Researchers do not define 'strong' or 'serious' concerns that parents were asked to consider, leaving this open to interpretation – limits internal validity • Content of the survey is unclear and the survey does not appear to be standardised – limits external validity • The potential for researcher bias is not considered – limits objectivity
Cunningham, McHolm, Boyle, & Patel (2004)	Canada	Unclear	*Sample:* • 104 children: 52 with SM (59.9% female, mean age of 7.2-years-old) and 52 without SM to act as a control group (matched on age and gender to the children with SM) • Parents and teachers	• Positive association between children's internalising difficulties (for example, anxiety and somatic complaints) reported by parents and SM, but no association between externalising difficulties (for example, challenging behavioural) and SM • No difference in family structure, family	*Strengths:* • Standardised measures with adequate internal consistency and validity • Large sample size – promotes external validity • SM group and controls were matched on demographics – promotes internal validity

			Design: • Quantitative *Method:* • Parents: Completed a battery of questionnaires and a structured interview • Teachers: Completed a battery of questionnaires and rated children's performance on reading and maths tasks • Children: Completed reading and arithmetic tests • Statistical analysis	functioning, or maternal mental health between children with and children without SM • No difference in academic and classroom cooperative skills between children with SM and children without SM • Children with SM scored significantly lower on measures of social skills, but were no more likely to be victimised by peers	*Limitations:* • Parent interview format is unclear – limits internal validity • No qualitative information – limits internal validity • Only included children with SM who had received a clinical service. It is possible that they represented a subgroup of children where SM had resulted in a more detrimental impact - limits external validity • Volunteer sample, indicating potential bias – limits internal validity • Academic assessments were administered at home, which were potentially less anxiety provoking than being conducted in the school context – limits internal validity

Alyanak, Kilinçaslan, Harmanci, Demirkaya, Yurtbay, & Vehid (2013)	Turkey	Unclear	*Sample:* • 26 children with SM (11 males, aged 5- to 13-years-old) and 32 controls (18 males, aged between 5- to 13-years old) and their parents *Design:* • Quantitative *Method:* • Parents: Completed a diagnostic interview and various structured questionnaires (to measure their parenting and emotional wellbeing) • Statistical analysis	• Parents rated children with SM higher on all measures of internalising and externalising difficulties, but scores were highest on internalising measures • No difference in parenting styles between parents of children with SM and those without SM • Fathers of children with SM displayed increased rates of anxiety, depression, a negative view of self, and somatisation compared to fathers in the control group • Correlation between severity of emotional and behavioural problems in children with SM and maternal psychopathology	*Strengths:* • Relatively large sample size – promotes generalisability • Standardised structured measures – promotes internal reliability • Accessed the views of both mothers and fathers – promotes internal validity *Limitations:* • Experimental and control groups of children were not matched on cognitive ability – limits internal validity • Only included children with SM who had been referred to a clinic. It is possible that they represented a subgroup of children where SM had resulted in a more detrimental impact – limits external validity • No qualitative data – limits internal validity

					• Results are correlational, meaning that causation is unknown – limits internal validity • Relied on self-report measures and its possible that parents were biased in their reports (for example, due to a possible social desirability effect) – limits internal validity
Christon, Robinson, Arnold, Lund, Vrana, & Southam-Gerow (2012)	USA	Cognitive behavioural	*Sample:* • 10-year-old girl and her mother *Design:* • Mixed methods *Method:* • Single case study of a young person who had engaged in a modular CBT programme • Data gathered through clinical interviews (mother and young person)	• Mother reported various detrimental effects of the SM on her daughter, including school refusal • Mother reported an increase in daughter's speech and independence and a decrease in her anxiety following the programme • Mother perceived the CBT programme to be helpful, but noted various barriers to	*Strengths:* • Multiple data collection methods – promotes dependability • Very detailed demographic information provided – promotes transferability *Limitations:* • Lack of information from mother (few verbatim quotes) – limits credibility

			and structured questionnaires (mother and young person) • No formal analysis	implementing strategies at home	• Lack of formal data analysis – limits confirmability • Researchers delivered the intervention and there is a lack of reflexivity, indicating a high chance of bias – limits confirmability • Small sample size – limits transferability
Albrigtsen, Eskeland, & Mæhle (2016)	Norway	Not explicitly stated, but included elements of a systemic approach	*Sample:* • One pair of identical male adolescent twins (aged 14-years-old) and their parents *Design:* • Qualitative *Method:* • Single case study • In-depth semi-structured interview with the twins and parents together two years after they had taken part in a	• Both the parents and twins reported many detrimental effects of the SM on themselves, on each other, and on the twins' younger sibling - significant effect on the whole family system • The parents reported that the multi-modal intervention had been effective in helping the twins to overcome their difficulty speaking.	*Strengths:* • Lots of qualitative information backed up by verbatim quotes – promotes credibility • Detailed demographic information provided – promotes confirmability *Limitations:* • Lack of a clear and rigorous data analysis procedure – limits dependability • The content of the interview (including the use of probes and

			multi-model intervention programme (including a 5-week stay at an inpatient family unit) • Interview was administered by one therapist and another therapist observed the interview • A form of thematic analysis		prompts) is unclear - limits dependability • Aspects of the intervention that were most effective is unclear (lack of clear conclusions) – limits credibility • Small sample size – limits transferability • The clinicians that interviewed the family and interpreted the data had already worked therapeutically with the family and there is no explicit evidence of reflexivity, suggesting a high risk of bias – limits confirmability
Bergman, Gonzalez, Piacentini, & Keller (2013)	USA	Cognitive behavioural	*Sample:* • 21 children with SM (aged 4- to 8-years-old) and their parents and teachers *Design:* • Quantitative	• Children who had taken part in the intervention demonstrated a reduction in social anxiety (as rated by the parents) and an increase in functional speaking (as rated by both the parents and teachers)	*Strengths:* • Independent evaluators (blind to treatment conditions) conducted pre- and post-intervention diagnostic interview - promotes objectivity

			Method: • Children were randomly assigned to 20 sessions of behavioural therapy over 24 weeks or a 12-week wait list condition • Parents: Completed a diagnostic interview and structured questionnaires • Teachers: Completed structured questionnaires • Children: Completed a narrative language assessment (administered by a teacher) and a series of verbal and non-verbal tasks (administered by a clinician) • Statistical analysis	• Parents and teachers reported a high level of satisfaction with the intervention	• Used standardised diagnostic interview that had demonstrated 'good' reliability • Used standardised questionnaires with 'excellent' to 'acceptable' internal consistency • Intervention sessions were videotaped and then randomly selected and rated for treatment adherence – promotes internal validity *Limitations:* • Wait list group was only 12 weeks in length which may not have been long enough to reflect natural reductions in anxiety – limits internal validity • No qualitative data – limits internal validity • Small sample size – limits external validity

Cornacchio, Furr, Sanchez, Hong, Feinberg, Tenenbaum, Del Busto, Bry, Poznanski, Miguel, Ollendick, Kurtz, and Comer (2019)	USA	Cognitive behavioural	*Sample:* • 29 children with SM (76% female, aged 5- to 9-years-old) and their parents and teachers *Design:* • Quantitative *Method:* • Children were randomly allocated to take part in an intensive (5-day) group behavioural intervention programme (delivered over the summer break) or a wait list group • Parents: Completed semi-structured diagnostic interview and structured questionnaires • Teachers: Completed Structured questionnaires	• Children who had taken part in the intervention made more significant gains in their verbal behaviour and demonstrated a greater reduction in social anxiety than the controls between baseline and week 4 (as reported by the parents and clinicians) • Teachers rated all children higher on measures of social and academic functioning once they returned to school • Parents reported a high level of satisfaction and a low level of barriers to engaging in the interviewing	*Strengths:* • Relatively large sample size and demographic information provided about the participants – promotes external validity • All clinicians were trained in the intervention programme and adherence checks were conducted to ensure that each clinician delivered the programme in the correct manner – promotes internal validity • Used standardised measures that have demonstrated 'good' reliability and validity • Children who were in the wait list condition still took part in the intervention programme, just at a later date – ethical

			• Clinicians: Completed structured questionnaires • Statistical analysis		• Independent evaluators administered the diagnostic interviews – promotes internal validity *Limitations:* • Some children were also taking anti-anxiety medication whilst engaging in the behavioural intervention, making it difficult to know what impact the intervention alone had – limits internal validity • The intervention programme was delivered over the summer break, meaning that the acute impact of the programme (i.e. on the child's communication in school) could not be measured properly – limits internal validity • Despite adherence checks some clinicians may have offered more 'emotional

					containment' than others – limits internal validity • Different teachers completed the questionnaires pre- and post-intervention – limits internal validity
Fisak, Oliveros, & Ehrenreich (2006)	USA	Cognitive behavioural	*Sample:* • 10-year-old boy and his mother and father and class teacher *Design:* • Mixed methods *Method:* • Single case study of a child who had engaged in a CBT programme • Data gathered through clinical assessment interviews, a semi-structured diagnostic interview, structured questionnaires, a	• Clinicians noted a gradually increase in child's speech within the therapy sessions • Parents and teacher reported a gradual increase in the child's social behaviour and speech outside of the therapy sessions • Parents found the intervention helpful, but noted various barriers to implementing strategies at home	*Strengths:* • In-depth demographic information provided – promotes transferability • Authors consider the mediating role of cultural factors - promotes credibility *Limitations:* • Lack of information from parents (few verbatim quotes) – limits credibility • Lack of formal qualitative data analysis – limits confirmability • Authors also delivered the intervention, indicating possible bias – limits confirmability

			social fear rating system, and regular conversations between the parents, teacher, and clinicians • No formal analysis		• Diagnostic interview was not re-administered post-intervention – limits confirmability • Small sample size – limits transferability
Pishva (2017)	Norway	Cognitive behavioural	*Sample:* • 19 mothers who had previously participated in a parent CBT programme • All mothers had a child who had been diagnosed with an 'anxiety disorder' (1 child had a diagnosis of SM) • Mean age of children: 10.7-years-old *Design:* • Qualitative *Method:* • All mothers completed individual	• Parents went through four stages of change in adopting the role of a therapeutic agent (helping their child to engage with and utilise CBT techniques) • The parents initially experienced an uncomfortable discrepancy between their natural parenting instincts and their need to implement CBT techniques • The parents gradually moved away from the role of a 'protector' that they had adopted and took on the role of a 'supporter'	*Strengths:* • Researcher addresses the process of reflexivity – promotes confirmability • Lots of qualitative information backed up by verbatim quotes – promotes credibility *Limitations:* • Only one child had a diagnosis of SM – limits credibility and transferability • The parents were interviewed an average of 1 year after they had completed the parent CBT programme, suggesting that elements of their narratives may have

			unstructured interviews (lasting 50 to 65 minutes) to explore their role in delivering CBT techniques • Used a grounded theory approach		been inaccurate (i.e. they may have forgotten elements of their experience) – limits credibility • Used a volunteer sample and all but one of the parents expressed positive views about the intervention, indicating the possibility of self-selection bias – limits credibility and transferability
Omdal (2008)	Norway	Unclear	*Sample:* • 5 children (2 boys and 3 girls, aged 3- to 13-years-old) attending pre-school, primary school, or secondary school • Parents and teachers *Design:* • Qualitative *Method:*	• Various barriers and facilitators to children overcoming SM • Facilitators: Clear communication between school staff and parents, staff actively promoting the child's social inclusion (i.e. involving them in classroom activities alongside their peers) • Barriers: School staff accepting the child's SM and removing	*Strengths:* • Parents and teachers received the interview schedules in advance, giving them time to consider their answers, which may have produced more accurate and detailed information– promotes credibility • Semi-structured interviews allowed for clarification – promotes credibility

			• Parents: Completed a semi-structured interview • Teachers: Completed a semi-structured interview • Children: Video-observed in school and at home over a 2-week period • A form of thematic analysis	opportunities for the child to speak and interact with their peers • Children in those settings that successfully promoted their social inclusion started to speak after a year, whereas children in those settings that failed to promote their social inclusion were still unable to speak at a one year follow-up	• Basic demographic information provided – promotes transferability • Multiple data collection methods – promotes dependability *Limitations:* • Small sample size – limits transferability • Less than 2 hours of video footage for four children and less than 1 hour of footage for one child – a very small snapshot • Unclear if more than one researcher analysed the data – limits credibility • Lack of evidence of reflexivity – limits confirmability

Appendix C: Invitation and Information Letter for Parents/Guardians

INVITATION FOR PARENTS/GUARDIANS TO TAKE PART IN A DOCTORAL RESEARCH STUDY

What are the Lived Experiences of Parents' Understanding and Supporting their Child with Selective Mutism? An Exploratory Study.

You are being invited to take part in a research study. Whether you agree to take part is completely up to you and before you make a decision it is important that you understand what the research would involve. Please take time to read the following information carefully.

Who is the researcher?
I am a postgraduate student in the School of Psychology at the University of East London currently completing a Doctorate in Educational and Child Psychology. As part of my training I am conducting the research you are being asked to take part in.

What is the research?
I am conducting research into parents' experiences of understanding and supporting a child with Selective Mutism. As part of this I am looking to interview parents (or legal guardians) of children who are currently experiencing difficulties in speaking at nursery or school despite being able to speak freely in other situations (for example, at home). You will be asked questions about your understanding of what led to your child's Selective Mutism and the impact, support you and your child have accessed, including support from your child's school and other professionals, and how helpful this has been, and how you have coped with your experience.

My aim is to give parents the opportunity to share their unique perspective, views, and experience. The purpose of this is to add to the existing lack of research and to help school staff and educational and health professionals to gain a deeper and more accurate understanding of Selective Mutism and the support that children may need. It is hoped that this will lead to earlier and more accurate recognition and earlier and more effective intervention.

The research will be approved by the School of Psychology Research Ethics Committee. This means that it will follow the standard of research ethics set by the British Psychological Society.

Can I take part?
You will need to be a parent or legal guardian of a child between 3- and 11-years-old who:

- Has received a formal diagnosis of Selective Mutism in the last five years AND is currently experiencing difficulties in speaking at nursery or school. You will need to provide evidence of this diagnosis prior to the interview (for example, via a letter from the appropriate service).

You will also need to be happy to give up 30-40 minutes of your time and be interviewed by the researcher.

What will my participation involve?
If you agree to participate you will be asked to sign a consent form. Once you have given consent the research will involve:

Interview:

- You will complete an interview (lasting approximately 30-40 minutes) on a one-to-one basis at a convenient time for you. This will take place in a public space (for example, a library, children's centre, or within your child's school) or via Skype.

- You will be asked a number of questions about your child and about your thoughts, feelings, actions, and experiences in relation to understanding and supporting your child and working with their school. There are no right or wrong answers – I am just interested in learning about your experiences. The interview will be similar to having a chat.

- The interview will be audio recorded (using a Dictaphone or the record function on Skype) and later transcribed.

Following the interview:

- I will share the findings with you (on a face-to-face basis, over email or phone, or via Skype) to confirm that they accurately represent your views and make any necessary changes.

- You may be invited to share the findings from the research alongside the researcher (for example, at conferences). This is optional and you will be asked to provide additional written consent.

Taking part will be safe and confidential:
Your privacy and safety will be respected at all times.

- Your name and contact details and all of the collected material and data will be securely stored. Only I will be able to identify you from the data collected. All information and material shared with others will be anonymised (your name will be changed) and will remain confidential. However, if I become concerned about the safety and wellbeing of your child or of yourself during the research I would need to report this information to other professionals.

- You do not have to answer all of the questions and can end the interview at any point.

What will happen to the information that you provide?

- Your name and personal contact details will be securely stored on an encrypted memory stick or external hard drive that only I have access to.

- Anonymised material and data collected (including transcripts from the interview), will be securely stored on a password protected laptop, on a secure cloud system (OneDrive) licenced by the University of East London, and on an encrypted memory stick or external hard drive that only I have access to. The audio recordings will be stored on a separate encrypted memory stick or hard drive.

- All data will be pseudo anonymised. This means that your data will be identifiable to myself and myself only. Your data will be anonymised before it is presented to anyone else and included in the write up of the research. Your identity will be protected with the use of a participant number and a different name.

- The following people may see the anonymised data: my first and second researcher supervisors and the rest of the course tutor team at university, research examiners, and other students and professionals. It may also be published in academic journals and shared at conferences attended by professionals, parents/guardians, and adult SM sufferers.

Once the study has been completed your consent letter will be deleted. However, the rest of the material and data will be stored for five years. This will include the interview recording and transcript to allow me to publish the findings. Your name and contact details will also be stored, so that I can invite you to assist with the sharing of the research findings. After the five years your name and contact details, alongside all of the material and data collected from you, will be destroyed.

What if I want to withdraw?
You are free to withdraw from the research study at any time without explanation or disadvantage. You may also request to have your data destroyed. However, I reserve the right to still use the anonymised data if it has already reached the point of analysis. If you wish to withdraw at any point you will need to contact me directly.

Potential risks to taking part:
The research may trigger some challenging feelings and thoughts due its sensitive nature. However, I will remain of aware of this and will offer you a break during the interview or suggest that we end the interview early if I become concerned about your wellbeing.

Potential advantages to taking part:
- This is an opportunity for you share your unique perspective, views, and experience.
- You will add to the existing lack of research around SM.
- You will help school staff and educational and health professionals to gain a deeper and more accurate understanding of Selective Mutism and the support that children may need and highlight improvements to practice. This will hopefully lead to earlier and more accurate recognition and earlier and more effective intervention.

Contact Details
If you would like to take part in this research or receive some further information, please do not hesitate to contact me. My email address is presented below:

- Name: Claire Douglas
- Email: u1825073@uel.ac.uk

If you have any questions or concerns about how the research will be or has been conducted please contact my research supervisor Dr. Lucy Browne. Address: School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: l.browne@uel.ac.uk

or

The Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas: Address: School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: t.lomas@uel.ac.uk

Thank you for taking the time to read this.

Kind regards,

Claire

Appendix D: Parent/Guardian Consent Form

PARENTS/GUARDIANS OF CHILDREN WITH SELECTIVE MUTISM

CONSENT TO PARTICIPATE IN A DOCTORAL RESEARCH STUDY

What are the Lived Experiences of Parents' Understanding and Supporting their Child with Selective Mutism? An Exploratory Study.

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have been able to discuss the details and ask questions about this information. I understand what my involvement will look like.

I understand that my involvement in this study, and the data gathered about myself and my child and the write up of the findings, will remain confidential. Only the researcher will have access to any identifying data. However, if the researcher develops concerns about the safety and wellbeing of me or my child during the research they will need to share information with other professionals. Should I wish to be involved in sharing the research findings at a later date (for example, at conferences) I also understand that my identity and involvement in the research may be revealed. However, I will be asked to complete a separate consent form as part of this. My identity will not be revealed without my formal consent. I also understand that the researcher will keep my personal information and data for up to five years following the write up of the findings. This will allow me to help with sharing the research findings (if I wish to).

I freely and fully consent to taking part in the research, which has been fully explained to me. I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also have the right to request for any data to be destroyed, but understand that the researcher reserves the right to still use my data if it has already reached the point of analysis.

Participant's Name (BLOCK CAPITALS)

…….

Participant's Signature

……..

Researcher's Name (BLOCK CAPITALS)

……

Researcher's Signature

……

Date: ……..…….

Appendix E: Ethical Approval Letter

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Shashika Vethanayagam

SUPERVISOR: **Lucy Browne**

STUDENT: Claire Douglas

Course: Professional Doctorate in Educational and Child Psychology

Title of proposed study: What are the Lived Experiences of Parents' Understanding and Supporting their Child with Selective Mutism? An Exploratory Study.

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data. Student's name *(Typed name to act as signature):* Student number: Date: *(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

☐ MEDIUM

☐ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: *Dr Shash Vethanayagam*

Date: 13th February 2020

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

Appendix F: Recruitment Trail

Table 1F

Table Detailing the Recruitment Process

Invitation Letters Sent Out (when and who)	**PP's who Expressed Interest (number, who, and when)**	**PP's Emailed to Confirm Met Inclusion Criteria (number, who and when)**	**PP's Who Replied To Email (number, who, and when)**	**PP's who Did Not Meet the Inclusion Criteria (number and why)**	**PP's who Met the Inclusion Criteria (number)**	**PP's who Signed and Returned the Consent Form (number and when)**	**PP's who Did Not Return the Consent Form (number and when)**	**PP's who Dropped Out (number, when, and why – if known)**	**Date of Skype Interview**
21/01/2020: Emailed SLT to share invitation letters with parents accessing a SM parent support network	**1 parent** Mother of a 4-year-old girl (26/02/2020)	**1 parent** Emailed Mother of a 4-year-old girl (26/02/2020)	**1 parent** Mother of a 4-year-old girl (27/02/2020)	0	**1 parent** Mother of a 4-year-old girl	**1 parent** Mother of a 4-year-old girl (28/03/2020)	0	0	**1 parent** 30/03/2020 Mother of a 4-year-old girl
21/01/2020:	0	-	-	-	-	-	-	-	-

Emailed all EPs to share invitation letters with SENCO's and headteachers at link primary schools									
03/03/2020 Posted invitation letter on SMiRA Facebook group for parents and professionals and SMiRA Facebook group for professionals.	**3 parents** Mother of a 12-year-old girl (04/03/2020) Mother of a girl – unknown age (06/03/2020) Mother of a 7-year-old boy (07/03/2020)	**3 parents** Mother of a 12-year-old girl (06/03/2020) Mother of a girl – unknown age (06/03/2020) Mother of a 7-year-old boy (07/03/2020)	**2 parents** Mother of a 12-year-old girl (09/03/2020) Mother of a 7-year-old boy (10/03/2020)	**1 parent** Mother of a 12-year-old girl (outside of age range)	**1 parent** Mother of a 7-year-old boy (10/03/2020)	**1 parent** Mother of a 7-year-old boy (14/03/2020)	0	0	**1 parent** 13/04/2020 Mother of a 7-year-old boy
23/04/2020 Posted invitation letter on SMiRA Facebook	**3 parents** Mother of a 3-year-old girl (23/04/2020)	**3 parents** Mother of a 3-year-old girl (23/04/2020)	**3 parents** Mother of a 3-year-old girl (24/04/2020)	**2 parents** Mother of a 10-year-old girl – known age	**1 parent**	**1 parent** Mother of a 3-year-old girl (07/05/2020)	0	0	**1 parent** 07/05/2020

group for parents and professionals and SMiRA Facebook group for professionals.	Mother of a 10-year-old girl (23/04/2020) Mother of a 6-year-old girl (23/04/2020)	Mother of a 10-year-old girl (23/04/2020 Mother of a 6-year-old girl (24/04/2020)	Mother of a 10-year-old girl (23/04/2020 Mother of a 6-year-old girl (25/04/2020)	(more than 5 years between diagnosis and current chronological age) Mother of a 6-year-old girl (no formal diagnosis letter)					Mother of a 3-year-old girl
04/05/2020 Emailed EPS to share invitation letters with SENCO's and headteachers at link primary schools	**2 parents** Mother of a girl – unknown age (06/05/2020) Mother of a 11-year-old girl (19/05/2020)	**2 parents** Mother of a girl – unknown age (06/05/2020) Mother of a 11-year-old girl (19/05/2020)	**2 parents** Mother of a girl – unknown age (06/05/2020) Mother of a 11-year-old girl (20/05/2020)	**2 parents** Mother of a girl – unknown age (diagnosis of speech disorder, not SM) Mother of a 11-year-old girl	0	-	-	-	-

				(no formal diagnosis letter)					
22/05/2020 Posted invitation letter on SMiRA Facebook group for parents and professionals and SMiRA Facebook group for professionals.	**6 parents** Mother of a 5-year-old girl (22/05/2020) Mother of a 7-year-old girl (23/05/2020) Mother – age and gender of child unknown (26/05/2020) Mother of a 7-year-old girl (26/05/2020) Mother of a 10-year-old girl (26/05/2020) Mother of a boy –	**6 parents** Mother of a 5-year-old girl (23/05/2020) Mother of a 7-year-old girl (25/05/2020) Mother – age and gender of child unknown (26/05/2020) Mother of a 7-year-old girl (26/05/2020) Mother of a 10-year-old girl (26/05/2020) Mother of a boy – unknown age (01/06/2020)	**6 parents** Mother of a 5-year-old girl (23/05/2020) Mother of a 7-year-old girl (25/05/2020) Mother – age and gender of child unknown (26/05/2020) Mother of a 7-year-old girl (26/05/2020) Mother of a 10-year-old girl (03/06/2020) Mother of a boy –	**4 parents** Mother of a 5-year-old girl (no formal diagnosis letter) Mother of a 7-year-old girl (living in Spain) Mother – age and gender of child unknown (no formal diagnosis letter) Mother of a 10-year-old girl (not willing to share	**2 parents** Mother of a 7-year-old girl Mother of a boy – unknown age	**1 parent** Mother of a 7-year-old girl (02/06/2020)	**1 parent** Mother of a boy – unknown age	0	**02/06/2020** Mother of a 7-year-old girl

	unknown age (01/06/2020)		unknown age (02/06/2020)	diagnosis letter)					
01/06/2020 Emailed SLT to share invitation letters with parents accessing a SM parent support network	**4 parents** Mother of a 5-year-old boy (01/06/2020) Mother of a 7-year-old boy (01/06/2020) Mother of a 7-year-old boy (02/06/2020) Mother of a 7-year-old girl (02/06/2020)	**4 parents** Mother of a 5-year-old boy (01/06/2020) Mother of a 7-year-old boy (01/06/2020) Mother of a 9-year-old boy (03/06/2020) Mother of a 7-year-old girl (03/06/2020)	**3 parents** Mother of a 7-year-old boy (01/06/2020) Mother of a 5-year-old boy (10/06/2020) Mother of a 7-year-old girl (07/06/2020)	**2 parents** Mother of a 5-year-old boy (no formal diagnosis letter) Mother of a 7-year-old girl (no formal diagnosis letter)	**1 parent** Mother of a 7-year-old boy	**1 parent** Mother of a 7-year-old boy (02/06/2020)	0	0	**1 parent** 07/06/2020 Mother of a 7-year-old boy
03/06/2020 Posted invitation letter on SMiRA Facebook group for	**8 parents** Mother of a girl – unknown age (03/06/2020)	**8 parents** Mother of a girl – unknown age (03/06/2020)	**5 parents** Mother of a girl – unknown age (03/06/2020)	**4 parents** Mother of a girl – unknown age	**1 parent** Mother of a 6-year-old girl	**1 parent** Mother of a 6-year-old girl (22/06/2020)	0	0	**1 parent** 22/06/2020 Mother of a 6-year-old girl

parents and professionals and SMiRA Facebook group for professionals.	Mother - unknown age and gender of child (03/06/2020) Mother of a 11-year-old boy (03/06/2020) Mother of a 5-year-old girl (03/06/2020) Mother of a 6-year-old girl (03/06/2020) Mother of a 11-year-old boy (03/06/2020) Mother of a 4-year-old girl (03/06/2020) Mother – unknown age and gender of	Mother – unknown age and gender of child (03/06/2020) Mother of a 11-year-old boy (03/06/2020) Mother of a 5-year-old girl (03/06/2020) Mother of a 6-year-old girl (03/06/2020) Mother of a 11-year-old boy (04/06/2020) Mother of a 4-year-old girl (04/06/2020) Mother – unknown age and gender of child (04/06/2020)	Mother of a 11-year-old boy (03/06/2020) Mother of a 5-year-old girl (03/06/2020) Mother of a 6-year-old girl (08/06/2020) Mother of a 11-year-old boy (10/06/2020)	(Mother was a SLT and had diagnosed her daughter herself – no formal diagnosis letter) Mother of a 11-year-old boy (more than 5 years between diagnosis and current chronological age) Mother of a 5-year-old girl (recently recovered/ overcome SM) Mother of a 11-year-old boy					

	child (04/06/2020)			(no formal diagnosis letter)					

Appendix G: Interview Schedule

Interview Questions

Demographic Questions about Parent:

1. How old are you?
2. What ethnicity do you identify as?
3. What is your occupation?
4. Which region of the country do you live in?

Demographic Questions about Child:

1. How old is your child (years and months)?
2. Is your child male or female?
3. What ethnicity does your child identify as?
4. Who lives at home with your child?
5. What year group is your child in at school?
6. How long have they experienced difficulties in speaking?
7. At what age did they receive a formal diagnosis of SM and who gave this diagnosis?
8. In what situations (and with who) does your child struggle to speak at the moment?

Probe:

- Do they communicate in any way (i.e. whispering, non-verbally) in these situations?

9. How do they present at home compared to school?
10. Has your child got any other diagnoses or primary needs?

Main Body

1. **Did you know much about Selective Mutism before your child was diagnosed?**

Prompts:

- If yes, what did you know and understand?
- If no, how did you then develop your knowledge?

Probe:

- What is your understanding of Selective Mutism now?/What do you think SM is?/How would you explain it?

2. **What do you think may have led to your child's difficulty in speaking?**

Probe:

- Do you think that your child's temperament or personality may have played a role (i.e. shyness)?

Prompt:

- If so, how?

Probe:

- Has your child suffered with any anxiety? Do you think this may have played a role?

Prompt:

- If so, how?

Probe:

- Is there a family history of SM or anxiety? Do you think this may have played a role?

Prompt:

- If so, how?

Probe:

- Has your child experienced any traumatic events that you feel may have contributed?

Prompt:

- If so, what are these and how did they contribute?

Probe:

- Has your child experienced Speech and Language difficulties? Do you think this may have played a role?

Prompt:

- If so, how?

Probe:

- Anything else that you think may have contributed?

3. **Has your child's difficulty in speaking impacted on them and their development?**

Prompt:

- If so, how?
- If not, why do you think that is?

Probe:

- Has it had any impact on their social life and relationships i.e. friendships, school staff, relatives?

Prompt:

- If so, how?

Probe:

- Has it had any impact on their learning and academic progress?

Prompt:

- If so, how?

Probe:

- Has it had any impact on their emotional wellbeing (i.e. self-esteem)?

Prompt:

- If so, how?

Probe:

- Has it had any impact on their independence or self-help skills (their ability to take care of themselves and meet their needs i.e. ask to go to the toilet)?

Prompt:

- If so, how?

Probe:

- Have there been any positive impacts?

Prompt:

- If so, what are these?

4. Has your child's difficulty in speaking impacted on yourself as a parent?

Prompt:

- If so, how and why?
- If not, why do you think that is?

Probes:

- Has it impacted your emotional health and wellbeing?

Prompt:

- If so, how?

Probe:

- Have there been any financial implications?

Prompt:

- If so, what have these been?

5. Has your child's difficulty in speaking impacted on the rest of the family?

Prompt:

- If so, on who and how?
- If not, why do you think that is?
- How has family life changed?
- How does this make you feel?

6. How did your child's nursery/school (i.e. class teacher) respond to the diagnosis?

Probe:

- Did they agree?
- Were they understanding and supportive?

Prompts:

- If so, what factors do you think contributed to their understanding?
- If not, why do you think this is?
- How did this make you feel?

7. What support has the nursery/school put into place?

Probe:

- Have they made any adaptations to the school setting or routine to accommodate for your child's difficulty speaking i.e. to enable them to communicate in a different way?

Prompt:

- If so, what adaptations have they made?
- What has been the impact of this?

Probe:

- Have they promoted your child's social inclusion with their peers in any way?

Prompt:

- If so, how? What has been the impact of this?

Probe:

- Have they set up and implemented specific interventions to reduce your child's anxiety?

Prompt:

- If so, what and how? What has been the impact of this?

Probe:

- Have they set up and implemented specific interventions to increase your child's talking i.e. Sliding-in?

Prompt:

- If so, what and how? What has been the impact of this?

Probe:

- Have they accessed support (or guidance) from outside professionals i.e. EP, SLT?

Prompt:

- If so, who and what have the professionals done?
- What has been the impact of this (i.e. increased the understanding by staff)?

Probe:

- Has the school involved you? (i.e. in setting up support or delivering interventions)

Prompt:

- If so, how (i.e. invited to meetings)? What has been the impact of this?

Probe:

- Have the school provided any other support?

Prompt:

- If so, what? What has been the impact of this?

Probe:

- Is there any support that the school were advised to put into place that they have not yet implemented?

Prompt:

- If so, what and why do you think this is? What has been the impact of this?

8. Has your child accessed any support outside of the nursery/school setting?

Prompts:

- Who has offered this support (i.e. NHS, LA, private organisations, family, friends)?
- What has the support consisted of?
- How did you identify and access this support?
- What led you to access this additional support?

9. Do you feel that your child has received enough support?

Prompt:

- If no, what impact do you feel this has had?
- What other support do you feel they need?
- Would any one form of support (i.e. from the school) be enough on its own?

Probe:

- Have you experienced any challenges or barriers to accessing support?

Prompt:

- If yes, what are these?
- How has this made you feel?

10. What support has been most effective for your child?

Prompt:

- Who has this support come from i.e. school, external agencies?

Probe:

- What support do you feel your child will continue to need going forward to overcome their SM?

11. Is there anything that has worsened you child's difficulty with speaking?

Probes:

- Anything inside nursery/school?
- Anything outside of nursery/school?

Prompt:

- How has this made you feel?

12. Is there anything that the school could do to better support your child?

Prompt:

- If yes, what?
- If no, why do you think that?

13. What support have you received or accessed as a parent?

Probe:

- What support has been most helpful for you?
- Have you met with any other parents who are in a similar situation? How did that feel?
- Have you received any support from the school?

Probe:

- Do you feel that you have accessed enough support?

Prompt:

- If not, what further support would be helpful? What would this look like/involve?

14. How do you think you have coped with your child's difficulty in speaking?

Prompts:

- Do you feel that you coped well?

Probes:

- If so, what has helped you to cope?
- If not, could you further explain why you think this?
- How have you dealt with your own thoughts and feelings?
- What advice would you give to other parents to enable them to cope?

15. Is there anything else that you would like other people and professionals to know about what it is like to have a child with Selective Mutism that we have not covered?

Appendix H: Debrief Letter for Parents/Guardians

DEBRIEF FOR PARENTS/GUARDIANS

What are the Lived Experiences of Parents' Understanding and Supporting their Child with Selective Mutism? An Exploratory Study.

Thank you for taking part in my doctoral research, exploring parents' experiences of understanding and supporting their child with Selective Mutism. I really appreciate your answers and hope that you enjoyed the opportunity to share your unique views. This will be hugely helpful in helping professionals to better understand Selective Mutism and the support that children and young people and their parents may benefit from.

I will now type up your answers to the questions and further explore what these may mean. I will then contact you to arrange a time to discuss my findings with you (on a face-to-face basis, over email or phone, or via Skype) to confirm that they accurately represent your views and make any necessary changes.

Your name and contact details will be stored securely on a password protected computer and on an encrypted memory stick or hard drive. All other material and data collected during the research process will be stored securely on a password protected laptop, on a secure cloud system (OneDrive) licensed by the University of East London, and on an additional encrypted memory stick. Only I will have access to these storage systems and only I will be able to identify you from the data collected and stored. All material and data will be anonymised before it is presented to anyone else and included in my write up. This means that I will not use your real name. However, if I have any concerns about the safety and wellbeing of yourself or your child I will need to share information with other professionals.

The following people may see the anonymised data collected: my first and second research supervisors and the rest of the course tutor team at university, research examiners, and other students and professionals. It may also be published in academic journals and shared at conferences attended by professionals, parents/guardians, and adult SM sufferers.

Once the study has been completed your signed consent letter will be immediately destroyed. However, the remaining information and collected data will be stored for five years to allow time for publication of the research findings and to invite you to assist with sharing the findings. After five years all information data (including your contact details, interview recordings, and transcripts) will be destroyed.

You have the right to withdraw any of your information, including your answers to the questions, without any explanation or disadvantage, up until when I start to analyse the data. If you wish to withdraw at any point you will need to contact me directly.

If you have any further questions you have time to ask them now or you can contact me at a later time. My contact details are presented below. If you feel that you need further support or advice for your child I would advise that you speak to the Special Educational Needs Coordinator (SENCo) at your child's school or your child's GP. You can also find further resources and support organisations at the bottom of this letter.

Thank you,

Claire

Contact Details

- Name: Claire Douglas
- Email: u1825073@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact my research supervsior Dr. Lucy Browne. Address: School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: l.browne@uel.ac.uk

or

The Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas: Address: School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: t.lomas@uel.ac.uk

Resources and Support Organisations

Selective Mutism information and Research Association (SMiRA):

http://www.selectivemutism.org.uk/

- This charitable organisation offers a website with information, resources, and advice. They also have a group on Facebook where parents can network with other parents and they hold an annual conference (usually in March) for parents and professionals.

National Health Service (NHS):

https://www.nhs.uk/conditions/selective-mutism/

- The NHS has set up a webpage with information about Selective Mutism and advice on how support may be accessed.

ISPEAK:

http://www.ispeak.org.uk/

- This website is run by a past sufferer of Selective Mutism and includes a bank of useful resources, including books, videos, and articles.

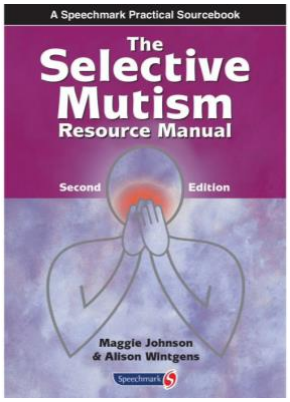
Young Minds:

https://youngminds.org.uk/

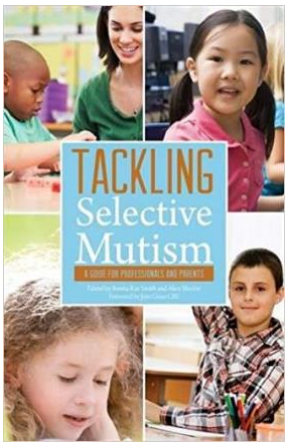
- Young Minds is a charity that offers advice and support around a range of mental health difficulties in children and young people, including anxiety.

Useful texts:

For parents and teachers:



The Selective Mutism Resource Manual (Second Edition) by Johnson & Wintgens (2016)

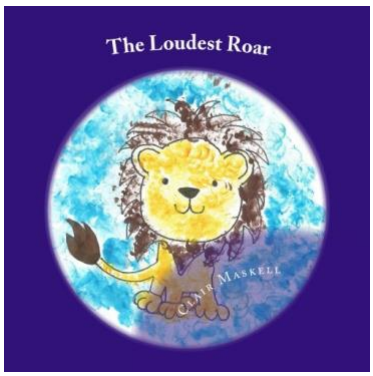


Tackling Selective Mutism by Sluckin and Smith (2014)

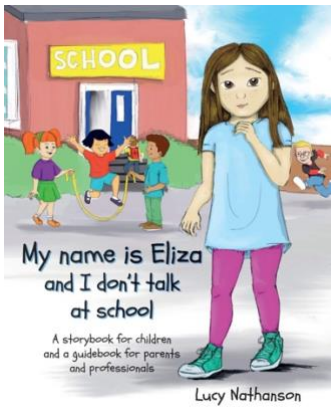
For children and young people:

Can I Tell You About Selective Mutism? By Johnson & Wintgens (2012)

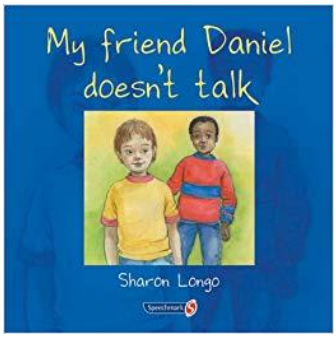
Maya's Voice by Cheng (2013)



The Loudest Roar by Maskell (2017)



My Name is Eliza and I Don't Talk in School by Nathanson (2018)



My Friend Daniel Doesn't Talk by Longo (2006)

Appendix I: Gantt Chart

	Key Dates		Days	Level of Completion	Month and Year																			
	Start Date	End Date	Number	Completed/Incomplete	Sep-19	Oct-19	Nov-19	Dec-19	Jan-19	Feb-20	Mar-20	Apr-20	May-20	Jun-20	Jul-20	Aug-20	Sep-20	Oct-20	Nov-20	Dec-20	Jan-21	Feb-21	Mar-21	Apr-21
Complete and submit research proposal	03/09/2019	25/11/2019	84	Completed																				
Complete and submit draft data management plan and draft ethics application form	18/11/2019	25/11/2019	8	Completed																				
Prepare interview materials (i.e. interview questions)	25/11/2019	02/03/2020	99	Completed																				
Amend and re-submit data management plan (and await approval)	13/12/2019	20/12/2019	8	Completed																				
Amend ethics application form (hold off on submitting until data management plan approved)	13/12/2019	20/12/2019	8	Completed																				
Re-submit ethics application (attach approved data manageemnt plan) and await approval	21/12/2019	13/01/2020	24	Completed																				
Register research (upload data management form, ethics form, and risk assessment)	13/01/2020	19/01/2020	7	Completed																				
Amend and re-submit data management plan (in light of Covid-19) and await approval	18/01/2020	26/03/2020	69	Completed																				
Recruit participants	23/01/2020	24/06/2020	154	Completed																				
Write methodology chapter (and complete reference list)	01/03/2020	07/05/2020	68	Completed																				
Conduct interviews	30/03/2020	22/06/2020	85	Completed																				
Thesis draft hand in window one (methodology chapter)	09/05/2020	30/05/2020	22	Completed																				
Conduct literature review and read papers	09/05/2020	23/05/2020	15	Completed																				
Write literature review chapter (and write reference list)	23/05/2020	07/07/2020	46	Completed																				
Transcribe interviews	01/06/2020	31/07/2020	61	Completed																				
Thesis draft hand in window two (literature review chapter)	08/07/2020	29/07/2020	22	Completed																				
Make ammendments to methodology chapter	08/07/2020	15/07/2020	8	Completed																				
Analyse data	16/07/2020	20/09/2020	67	Completed																				
Make ammendments to literature review chapter	30/07/2020	07/08/2020	9	Completed																				
Write findings chapter (and complete reference list)	21/09/2020	21/11/2020	62	Completed																				
Check findings (member check) with participants	30/10/2020	12/11/2020	14	Completed																				
Thesis draft hand in window three (findings chapter)	21/11/2020	12/12/2020	22	Completed																				
Write introduction chapter (and complete reference list)	30/11/2020	02/01/2021	34	Completed																				
Make ammendments to findings chapter	13/12/2020	23/12/2020	11	Completed																				
Write discussion chapter (and complete reference list)	03/01/2021	11/02/2021	40	Completed																				
Thesis draft hand in window four (introduction and discussion chapters and whole thesis)	12/02/2021	05/03/2021	22	Completed																				
Make ammendments to introduction and discussion chapters and thesis as a whole	06/03/2021	16/03/2021	11	Completed																				
Proof read, check references, print, and bound	16/03/2021	29/03/2021	14	Completed																				
Hand in/submit thesis	29/03/2021	29/03/2021	1	Completed																				

Key to Chart	
	Research propsal
	Preparation stage
	Ethical approval/DMP
	Registration
	Introduction
	Method
	Literature Review
	Analysis/Findings
	Discussion
	Hand in

Appendix J: Part of Two Coded Transcripts (Initial Noting and Emergent Themes)

Transcript from Interview One (Anna)

Analysis of Anna's (PP 1) Interview			
Emergent Themes	**Line no**	**Original Transcript**	**Exploratory Comments/Notes**
		I – Interviewer A – Anna	Descriptive: Content *Linguistic: Language features* Conceptual: PPs understanding/sense making – more interpretative (E.g. Is she confused about what she went through?)
		PROVIDED INTRODUCTION **DEMOGRAPHIC QUESTIONS** **STARTED RECORDING**	
	1 2 3 4 5 6 7 8	**I:** Oh. Ok so it said that it has started recording, so that's good [laughs]. **A:** Oh yeah, I can see that yeah [Laughs]. **I:** Ok cool. Erm, and how long has she experienced difficulties in talking?	
Early onset First identified by nursery	9 10 11 12 13 14	**A:** Er, she was about two and a half, erm we ….(pause)….no actually [thinking facial expression] three, three, because we put her in nursery when she was three and I think it was within the first week of nursery they said to me "she doesn't talk, have you got a speech therapist?". And I thought it was really strange, why	Early onset. *Pause and uses words "actually" and "think" – foggy memory?* Didn't initially suspect that Elizabeth was struggling to speak? Difficulties in speaking picked up in nursery by nursery staff.

	15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46	would they say <u>that</u> [emphasis on word] and that's when we really noticed that there was a problem. **I:** Yeah, ok, ok. Erm, and what age did she get the diagnosis of Selective Mutism? **A:** She got that….(pause)….erm at the end of October 2019. **I:** Ok, so quite recently then. **A:** [Nods] very quickly yeah as well. **I:** Ok [nods] and who gave the diagnosis? **A:** It was a lady called ____(Name of SLT), er Speech and Language Therapist. We, I went on training with ____(Name of SLT) and it was her who told me to refer [nods]. **I:** Yeah [nods], ok. **A:** And we got through quite quickly on that as you can imagine [laughs]. **I:** Yeah no you got the right person involved that's for sure [laughs]. **A:** Yes, amazing yeah [laughs]. **I:** Erm, and in what situations at the moment does she struggle to talk in?	*Pause – foggy memory?* <u>Perhaps a lot has happened since the diagnosis?</u> <u>Perhaps felt like a long journey?</u> Quick diagnosis. Diagnosis provided by NHS SLT. <u>Is whether parents can access a formal diagnosis dependent on where they live within the UK?</u> Advised to refer for SLT assessment by a SLT providing SM training. <u>Believes that the SLT delivering the SM training helped her child to access an assessment and diagnosis? This SLT seemed to play a key role in guiding the parent.</u>
Recent diagnosis Diagnosed by SLT (NHS)			

Different child at home   'Shut down' as self-protection

Pulled out of nursery	79 80 81 82 83 84 85 86 87 88 89 90	**A:** She was, she started when she was two….(pause)….erm and we've just pulled her out, it wasn't quite two years, we have just pulled her out, erm, she is with a child minder now. We pulled her out about three or four weeks ago. **I:** Ok, ok. And how has she been with the child minder? **A:** Er on the first day she actually spoke to the child minder [smiles and raises eye brows]. **I:** Oh wow [smiles and raises eye brows].	*Uses the phrase "pulled her out" and repeats this same phrase – seems more extreme than "taken her out".* Perhaps felt like she was rescuing her daughter? Now attending a childminders rather than nursery. Speaks to the childminder. Less anxious than she was in nursery? *Smiles and raises eye brows – A is surprised but happy by this?* Is A relieved that her daughter is less anxious with a childminder? Shocked by ability to communicate with childminder immediately on a 1:1 basis. *Uses the words "only" and "very" – emphasises that speaking is still limited.*
The power of animals Dedicated childminder	91 92 93 94 95 96 97 98 99 100 101	**A:** So we were quite shocked by that [laughs]. It was only like very quietly, erm, and she won't speak to any of the other children yet, but when it was on a one-to-one with the child minder she spoke to her. Erm, and the childminder….(pauses)….she (Elizabeth) loves animals, so the child minder has got a dog and Elizabeth went out for a dog walk on a one-to-one with her and apparently she was chatting away on the dog walk. **I:** Aww wow [smiles].	Won't speak to other children. *Uses the word "yet" – sense of hope that will continue to make progress?* Dog walk helped Elizabeth to open up. *Uses the word "love" – emphasises how much Elizabeth likes animals.* Believes that animals help Elizabeth to feel more comfortable and to open up? What is it about animals? Perhaps they feel less threatening as they don't expect/need Elizabeth to speak? Shared interest in animals with childminder. Does A believe that this will act as a basis to Elizabeth feeling more comfortable and less anxious?
Dedicated childminder The power of animals	102 103 104 105 106 107 108 109 110	**A:** So she has got a little niche with her already, which is lovely [smiles], 'cause all that time at nursery that didn't happen for her, so we're really pleased we moved her [nods]. **I:** Yeah, it's amazing what dogs can do as well isn't it [smiles]? **A:** Yeah, yeah [smiles and raises eye brows]. She always talks to animals, like she will sit on the floor and chat to a dog even if it is in room full of people.	Closer relationship with childminder than nursery staff. Pleased that swapped nursery for childminder. *Uses happy tone of voice and the word "really" – sense of relief?* Talks freely to animals. *Uses the word "always" – emphasises how there is a difference between how Elizabeth reacts to animals v's people.* What is it about animals? Perhaps they feel less threatening as they don't expect/need Elizabeth to speak? *Laughter – finds it humorous that Elizabeth finds it easier to talk to animals.*

	111		
	112	**I:** Does she? [smiles and laughs].	Finds it strange that able to talk freely to animals even in front of other people. *Uses the word "strange" – perhaps feels confused or is not able to make sense of this?*
	113		
	114	**A:** Yeah [laughs].	Recognises that there is no pressure to speak with animals.
	115		
	116	**I:** Aw.	
	117		
	118	**A:** That's strange as well, but yeah [smiles].	
	119		
	120	**I:** Aw.	
	121		
The power of animals	122	**A:** No pressure with a dog is there [shrugs shoulders and laughs]?	
	123		
	124	**I:** No [Laughs]. Fantastic. Erm, ok and when she is out in the	
	125	community, does she communicate in any way? Does she	Can whisper when out in the community if others are not too close.
	126	whisper, does she use gestures?	*Repeats "really, really" – emphasises that communication is still limited when out in the community.*
	127		
	128	**A:** Yeah. I mean if people are all really really close to her she	Shuts down if there is an expectation to talk. It's the expectation she struggles with?
	129	will whisper and she will get really close to my ear and she will	
'Shut down' as self-protection	130	whisper. Erm, if it's a supermarket and they (other people) are	*Uses the phrase "shut down" – implies that becomes withdrawn?*
	131	all quite far away from her, she will talk completely normally.	Is it like Elizabeth is no longer there?
	132	It's only if people come too close and she thinks there is some	
	133	kind of expectation on her, then she will shut down.	
	134		
	135	**I:** Ok, ok. And how is she at home compared to when out in the	
	136	community?	
	137		Different child at home. *Laughs – finds it humorous that daughter is so different at home.*
Different child at home	138	**A:** Oh you would never know [laughs].	
	139		
	140	**I:** Really? [smiles].	
	141		Different child at home.
	142		Chatterbox at home.

Different child at home	143 144 145 146 147 148 149 150 151 152	**A:** She is like a tornado [laughs], she's running around, chatterbox. She has got lovely language and she, yeah she never stops talking [laughs]. **I:** [Smiles]. It is often the way isn't it (with Selective Mutism)? **A:** Yeah [nods]. **I:** Aw ok. Erm, and has she got any other diagnoses?	Good language skills.
Diagnosis of ASD	153 154 155 156 157 158 159	**A:** She has got Autism, erm let me just check her thing, see what they say [looks at report]. She has got Autism, she has got PICA, erm don't see that as much now, but yeah it's still every now and again, finds a bug or a bit of wallpaper. **I:** Ok.	Diagnosis of Autism. Diagnosis of PICA. Multiple co-morbidities. *Refers to needing to check a report, suggesting that Elizabeth has multiple complex needs.*
High anxiety	160 161 162 163 164 165 166 167 168 169 170 171 172 173 174	**A:** Yeah, she's got sensory processing. It is mostly things connected with Autism, like anxiety, er she has got very very high anxiety, erm, that's part of SM as well isn't it? Erm and I think that's all she's got actually. **I:** And was the Selective Mutism diagnosed before (ASD)? **A:** Yeah Selective Mutism is on there as well, yeah. **I:** And was that before the Autism? **A:** That was after. **I:** Afterwards, ok.	Sensory processing difficulties. High anxiety. *Says "very very high" – emphasises extent of anxiety.* Believes that anxiety is connected to diagnosis of ASD and diagnosis of SM?

Diagnosis of ASD	175 176 177 178 179 180 181 182 183 184 185 186 187 188 189 190 191 192 193 194 195 196 197 198 199 200 201 202 203 204 205 206	**A:** I didn't think the two (SM and ASD) could sit together, 'cause they never used to be able to, you could only get one diagnosis or the other, but now we are ok with that so. **I:** So how old was she when she had the Autism diagnosis? **A:** She was….(pause)….not sure, I think she was almost three. **I:** Ok. **A:** I've got the date here hang on a minute [looks at report], er April 2019. **I:** Ok. **A:** Yeah, April 2019. She was diagnosed on the day. **I:** Ok, ok. And who lives at home at the moment with Elizabeth? **A:** Er me and Dad, erm, and her brother, (Brother's Name). **I:** Oh brilliant and how old is (Brother's Name)? **A:** He is six, er he is going to be seven in May. **I:** Aw [smiles]. **A:** He's also Autistic. **I:** Is he? Ok. **A:** Another chatterbox [laughs].	SM diagnosed following ASD diagnosis. ASD noticeable a bit earlier on? Initially didn't know that it was possible to get a diagnosis of ASD and SM. Feels ok that daughter has a diagnosis of ASD and a diagnosis of SM. *Pause – hesitant – foggy memory of when Elizabeth was diagnosed with ASD?* Perhaps it has all been a bit overwhelming? Reliant on reports to recall when Elizabeth received diagnoses. Diagnosed with SM six months after ASD. Nuclear family. 6-year-old brother. Brother also has a diagnosis of ASD.
Family history of ASD			

	207		
	208	**I:** You have got your hands full [smiles].	
	209		
	210	**A:** Oh yes, oh yes [laughs].	
	211		
	212	**I:** [Laughs]. Ok, fantastic, thank you. Erm, so how like, did you	
	213	know much about Autism before Elizabeth was diagnosed?	
	214		
	215	**A:** Yeah, I used to do Speech and Language Therapy. I ran the	Previously a SLT technician.
	216	clinic for Autism before I left, I was a technician and in	Knowledgeable about ASD prior to her children receiving a
	217	____(Name of Town) I ran the clinic and all the Autistic children	diagnosis, but learnt even more since children have been
	218	used to come to me and I ran all of the therapy for them. So I	diagnosed.
	219	knew, I thought I knew quite a lot, but then having a child with	
	220	Autism it kind of opened my eyes to a lot more. But yes I already	
	221	had quite a good understanding of it, which was really helpful	
	222	[nods].	
	223		
	224	**I:** Yeah and what was your understanding of Selective Mutism?	
	225		
Lack of understanding	226	**A:** Er Selective Mutism [sighs], I didn't have much of an	Lack of understanding of SM prior to daughter being diagnosed.
	227	understanding of that, it was more the Autism. Selective Mutism,	*Sighs – perhaps frustrated by lack of understanding?*
	228	I met a child once who I was told was a Selective Mute, erm, and	Greater understanding of ASD than SM.
	229	I took her out of the classroom and she talked to me completely	Does A feel less confident talking about SM than ASD?
	230	normally and she'd never met me before, so I thought I don't	Some professional experience in working with children with SM,
	231	think she's a Selective Mute unless I've got a magic wand. But	but still lacked an understanding.
	232	erm, yeah my understanding of Selective Mutism, I'd done the	Difficulty distinguishing between ASD and SM. Element of
	233	sliding in, erm, programme very briefly, but it was kind of, a very	confusion about what could explain her daughter's behaviour e.g.
	234	kind of sketchy understanding that I had and I found it very	lack of eye contact, not wanting to initiate. Traits of SM and ASD
	235	difficult to pick between Autism and Selective Mutism, 'cause	overlap.
	236	they were looking the same to me. Things like the lack of eye	
	237	contact with Elizabeth I couldn't ever work out if that was ASD	
	238		

	239	or if it was SM, she just didn't want to initiate, so I found it quite	
	240	difficult to separate the two.	
	241		
	242	**I:** Yeah, yeah [nods].	
	243		
Lack of understanding	244	**A:** But for me Selective Mutism, I thought it was just when other	Basic understanding of SM prior to training and diagnosis. Was this understanding due to A's background in SLT? May be the other parents wouldn't have even had the basic understanding?
	245	people were there she might not speak. It was quite, quite a basic	
	246	understanding that I had.	
	247		
	248	**I:** Yeah, yeah [nods].	
	249		
Training and Advice from SLT course	250	**A:** And ____(Name of SLT) was amazing. That whole training I	Appreciative of SLT delivering SM training. *Uses the word "amazing" – emphasises what a positive experience it was.* Perhaps the training provided clarity and an explanation for her daughter's presentation? Sense of relief?
	251	sat nodding all the way through [nods and laughs].	
	252		
	253	**I:** It is like a two day course she does?	
	254		
Training and Advice from SLT course	255	**A:** No she did it, it was just a morning at a little children's centre	Half a day free SM training delivered by SLT. *Uses the word "incredible" – emphasises what a positive experience it was.* Agreed with everything said at the training. *Laughs – perhaps couldn't believe how accurately the training described Elizabeth? Uses the phrase "it was a real moment" –implies that the training is a strong memory* – First time she had properly understood her daughter? Sense of relief?
	256	here, 'cause she works in this area, I had no idea she worked in	
	257	this area, and she ran a mornings training, erm, for parents and	
	258	professionals and it was free. I was, erm, the speech therapist said	
	259	that I should go along, so I did. Yeah it was incredible, just	
	260	everything she said I was like "yes yes" [nods and laughs], it was	
	261	a real moment.	
	262		
	263	**I:** Wow [Nods and laughs]. Ok, brilliant. Erm, and what do you	
	264	think might have led to Elizabeth's difficulty in speaking?	
	265		
Uncertainty about the cause	266	**A:** I've absolutely no idea. I mean she's very anxious, but, but	Unsure of what led to onset of SM. *Uses the word "absolutely" – emphasises lack of certainty.*
	267	no idea apart from the anxiety, that's all I can think, but yeah,	
	268	there has been no traumatic experiences. I mean even from a	Anxious from a baby (when first born). *Emphasises "screamed" – emphasises level of anxiety.*
Early onset	269	baby I, I couldn't leave her. I mean like the second day in hospital	
	270	I needed to go to the toilet and the minute I left she screamed	

	271	[emphasis on word] the ward down, so she's always been	
	272	anxious even right from [gestures going backwards with hand].	
	273		
	274	**I:** Yeah [nods].	
	275		
Early onset	276	**A:** And I noticed that straight away with her, like the minute I	Separation anxiety as a baby – got upset whenever A left the room.
	277	left the room, she would go berserk, so I had to have a little	*Uses word "berserk" – suggests that Elizabeth's reaction was*
	278	Caboo carrier [gestures holding a baby carrier on her chest] and	*extreme.*
	279	just take her everywhere with me.	Elizabeth had to be attached to Mother.
	280		
	281	**I:** Aw [smiles].	
	282		
Early onset	283	**A:** Like a baby kangaroo, you know [laughs]. But yeah she has	*Metaphor – "like a baby kangaroo" – emphasises Elizabeth's*
Uncertainty about	284	always been very anxious [nods] and I don't know, I don't know	*vulnerability and how she had to always be attached to her*
the cause	285	where that has come from.	*Mother.*
	286		Unsure about why Elizabeth is so anxious. Element of confusion?
	287	**I:** Yeah. Do you think it's part of her temperament and	
	288	personality that she's shy?	
	289		
	290	**A:** It could be, yeah, it could well be. She's not very shy, like	Doesn't believe that SM is due to shyness. *Uses phrase "at all"*
Not due to shyness	291	especially around the house, she doesn't come across as shy at	*to emphasise this.*
	292	all, but obviously out and about you see a different side to her.	Different child outside of the safety of the family home. Family
	293		home acts as a safe base?
	294	**I:** Yeah [nods]. Yeah, ok, ok. Erm, and you said that she's	
	295	suffered with anxiety since she was a baby?	
	296		
	297	**A:** Oh yes, yeah [nods].	Anxious as a baby.
	298		
	299	**I:** And how does that come out? How do you see that?	
	300		
Seeks reassurance	301	**A:** Erm, well she doesn't leave your side, like if I'm having a	Doesn't leave A's side.
from Mother	302	bath she's there. She won't go and play with her Barbies on her	

Transcript from Interview Six (Steph)

Mother fighting for support   Support from professionals

Lack of a knowledgeable and dedicated teacher (year one) Mother fighting for support Discrepancy between what the teacher said he would do and what he did	401 402 403 404 405 406 407 408 409 410 411 412 413 414 415 416 417 418 419 420 421 422 423 424 425 426 427 428 429 430 431 432	**I:** Ok, ok. Have the school accessed any training on Selective Mutism? **S:** [Shakes head]. **I:** No, ok. It's really sad that there's such a lack of awareness isn't there? **S:** Well it's really frustrating, especially as her, yeah so at the end of Reception I had a couple of transition meetings with her year one teacher who is….(pause)….you know and I know some young teachers can be amazing but he's quite young and so therefore not loads of experience, he's normally been used to teaching year five and six, so this is the first year one group he has had. And he did the whole, he's a bit of, puts on a good show you know, "yeah, yeah, I'll do anything, I just want her to be comfortable, that's great" and we talked about sliding in. I said it would be really good if I could come in, but it really needs you to be involved in that and dah dah, "yeah yeah, absolutely, whatever whatever whatever". And then, erm, and then he said "yeah and you know over the holidays email me if there's anything", so I did and I emailed and I said "I would really [emphasis on word] appreciate if you would do a bit of reading up about it and gave references and I said "there's also this Facebook group", which, erm, I had seen other teachers post on saying I've got this child about to come into my class, and like every time I saw those I thought oh how amazing, but no he didn't do any [emphasis on word] of that [shakes head]. And he'd also said at the end "and yeah you can come in on one of the inset days before term the starts, come in so she can see the classroom and just with you and", so I tried to get into contact so many times and no one ever, I couldn't get hold of him or anyone,	*Sighs* – sense of frustration? All staff listened to the Reception teacher. It was all down to her Reception teacher. Only reception teacher was knowledgeable. Limited understanding amongst the rest of the school staff. Year one teacher has been *"rubbish"* – less supportive. School have not accessed any SM training. Frustrated by lack of understanding in school. Year one teacher is less experienced. Year one teacher appeared committed and dedicated but failed to do what he said he would. Year one teacher has not been supportive. Mother spoke to teacher about sliding in technique and offered to come into the school to support. Mother determined to help. Mother advocating for Hazel. Mother emphasised that teacher needed to be involved in delivering the sliding in technique. Mother taking the lead in organising interventions. Mother suggesting support. Mother requested teacher to read up on SM. Mother directed teacher to books and FB group. Mother keen for teacher to self-educate/learn about SM. Mother fighting for year one teacher to understand SM. Teacher didn't engage in self-education/access information resources. Did this result in Steph feeling disempowered? Teacher wanted to help but this desire did not transmit into actions. Teacher offered Hazel to visit classroom as part of her transition, but Mother was unable to contact anyone over the summer.

	433	so we couldn't do that. It just felt a bit half hearted and like it was all	Teacher was *"half hearted"* – lacked enthusiasm. It was *"all*
	434	talk really.	*talk"*. Teacher was not very proactive? Teacher didn't seem
	435		to make an effort to learn more about SM? Perhaps this was
	436	**I:** Yeah.	due to the teacher having greater priorities or not
	437		understanding the significance of SM?
Lack of a	438	**S:** And then yeah all the sliding in….(pause)….hasn't been that great,	
knowledgeable and	439	because he basically just kept leaving the classroom and not coming	Teacher struggled to deliver sliding in technique – kept
dedicated teacher	440	back, it's just really annoying [frowns], he'd go "oh yeah yeah", and	leaving the classroom and wouldn't come back. Teacher
(year one)	441	he also speaks to her like she's got really special needs [laughs].	struggled to deliver interventions, perhaps due to competing
	442		demands or not fully understanding/grasping SM?
	443	**I:** That's not helpful is it [smiles].	Teacher not delivering sliding in technique properly was
	444		annoying. Element of frustration?
	445	**S:** Gosh it's so stupid, he goes, she's sitting next to me and he goes	Speaks to her like she's got really special need - patronising –
	446	"oh yeah erm", sorry he's Australian, I find it really difficult to do an	Is this related to a lack of understanding of what SM is?
	447	Australian accent [laughs].	*Use of humour to explain how teacher comes across as*
	448		*patronising.*
	449	**I:** No it's fine [shakes head and laughs].	Teacher speaks to Hazel in a patronising manner – Is this due
	450		to his lack of understanding of what SM is?
Lack of a	451	**S:** But he goes "I'm just going to go to the office, I will be back in	Uses the phrase "god you don't really get this do you" -
knowledgeable and	452	five minutes" and then he goes "Hazel, Hazel I'm just gonna go to	Teacher doesn't understand – frustrated by this. Teacher
dedicated teacher	453	the office" and she's like yeah I just heard you. It's like god you don't	would leave and wouldn't return during sliding in sessions.
(year one)	454	really get this do you [shakes head]. Anyway so he would go off for	Mother got frustrated by this. Lack of support from teacher
Impact on the	455	five minutes and not come back [shakes head] and so I would be	impacted on Mother's emotional wellbeing.
mother's emotional	456	really frustrated and I've like dragged my little one in there and it's	Frustrated as had also dragged younger child into the school.
wellbeing	457	you know and argh [fed up facial expression].	Impact on younger sibling.
	458		*Says "argh"* – high frustration.
	459	**I:** So the sliding in technique, did you do that Reception as well or	Lack of commitment/dedication from teacher.
	460	just year one?	Difficulty implementing interventions in the school setting.
	461		
Lack of resources to	462	**S:** We tried in Reception. To be honest in Reception the teachers were	Teacher wanted to help but too busy.
implement	463	so lovely and wonderful and really wanted to do it, but they were too	Teacher attempted sliding in technique but too many other
interventions	464	[emphasis on word] busy to do it properly basically. And I could see	competing demands. Teacher would get pulled out of the

	465 466 467 468 469 470 471 472 473 474 475 476 477 478 479 480 481 482 483 484 485 486 487 488 489 490 491 492 493 494 495 496	that they were finding it frustrating, like there were a couple of times where someone would come and go and they kind of pull the teacher out of the classroom and she'd go oh I'm so sorry and you know it wasn't, I felt like she would have, she would reply to emails at ten at night, you know she was, it wasn't through lack of trying [nods]. But we haven't really been able to do it properly [shakes head], because we haven't been given any protected time for it or, or you know there's been nothing….(pause)….erm no set agreement around it, I think that's been the problem with it. **I:** Ok. And so did you start the sliding in in September in year one properly, well tried to? **S:** Yeah, well tried to. Yeah so, but it's tricky 'cause I do shifts as well and then I look after somebody else's children one day a week and I'm, you know so there's very little availability to actually be able to do it. Erm, so it has been, it's been a really difficult thing to achieve and I just don't think we've done it properly [shakes head] and the teachers haven't, you know the thing is it doesn't work unless they are there does it? **I:** Were, were you sort of going into school every day or every few days? **S:** No, we were only managing it about once a week and then we started to try and do it, erm, more recently I was like we've got to try and do this better, but I didn't have enough, I didn't have enough after schools where I could do it, because of work and looking after somebody else's child and my partner, he doesn't get home until seven. So then one day a week he takes her to school so we were, he started going in earlier on one day, erm, and so they did a bit in the	question during sliding in sessions. Teacher felt frustrated by this. Teachers wanted to help, but lack of resources to do so. Teacher was frustrated by this. Lack of resources in school setting (i.e. lack of staff) acted as a barrier to staff implementing interventions i.e. sliding in technique. Teacher would reply to emails at 10pm. Teacher wanted to help. Uses the phrase *"it wasn't through lack of trying"*. Teachers wanted to help, but lack of resources to do so. Discrepancy between desire to help and implementing support/interventions. Teachers have been given no protected time to focus on sliding in process. There has been no set agreement. This is why it hasn't worked. Time for intervention is not prioritised by the school, which has acted as a barrier to Hazel being supported effectively. Mother has to juggle many demands. Finding time to assist with interventions is a struggle due to everyday demands i.e. work. Sliding in technique has been difficult for both Steph and the school staff to deliver. Many barriers, including time. Mother found it difficult to find time to assist with interventions. Mother pushed for her and the school to be more consistent and organised in delivering the sliding in intervention. Mother taking charge. Advocating for her daughter. Parents made adaptations i.e. took Hazel into school earlier to do sliding in process. Parents looking for ways to overcome the barrier of time. Parents keen to help daughter.
Lack of resources to implement interventions			
Lack of resources to implement interventions			

	497 498 499	morning and then I would try and do one afternoon so then we were doing it twice. Erm, but then lockdown happened [smiles].	Had to stop sliding in process due to Covid-19 lockdown. Covid-19 has disrupted support.
	500 501	**I:** Yeah, nightmare [laughs].	
	502 503 504	**S:** Yep, exactly. So yeah it hasn't been very successful at all [shakes head], which is a bit of a shame.	
	505 506 507	**I:** That's really difficult and a lot of parent's I've spoken to have said similar things and it's sad and really frustrating.	
	508 509 510	**S:** Yeah, really frustrating, really frustrating [concerned facial expression].	Frustrated by disruption caused by Covid-19 lockdown.
	511 512 513 514	**I:** And, erm, in terms of what you think might have triggered the Selective Mutism for Hazel, what, what do you think that might have been?	
Genetics contributed to onset Early onset	515 516 517 518 519 520 521 522 523 524	**S:** No yeah I don't know, I, I feel like….(pause)….erm, I know the jury's out slightly on whether anxiety can be genetic or not, but I think it might be for her because she was showing signs of it from such [emphasis on word] a very young age and I totally get that I could have influenced that and I am someone who suffers with anxiety and so is her dad, so you know if you're gonna have a genetic predisposition than she would. But having said that I think, you know I wasn't anxious through my pregnancy, I felt happier than I've ever felt 'cause all I've ever wanted is to have babies [laughs]. And, erm, I was a very confident Mum because I'd been around babies so much,	SM is due to genetics. Showed signs of anxiety from a young baby. Steph and Hazel's Father suffer with anxiety. Family history of anxiety. Genetic predisposition to developing anxiety. Wasn't anxious during pregnancy. Confident Mum. Lovely relationship. No post-natal depression. Good attachment. Ruled out other possible explanations i.e. trauma/environmental factors to onset of SM?
Not due to environmental factors	525 526 527 528	you know I breastfed her, she slept with me, she breastfed for over two years, she, she was in, I carried her in, you know we had, we had a lovely relationship, you know I didn't have any post-natal depression. We had a good attachment and she was really socialised	No clear environmental triggers.

	529	from straight away, you know there were people that she saw like my	
	530	mum and I mean that she had that kind of thing where you have	
	531	certain people that you're you know, so I feel like no there didn't	
	532	seem to be any big event put it that way.	
	533		
	534	**I:** Yeah, it sounds like you had a really good attachment with her,	
	535	which is really positive [smiles].	
	536		
	537	**S:** Yeah, yeah.	
	538		
	539	**I:** And in terms of family history of anxiety, is there a history in	
	540	grandparents, aunts and uncles as well?	
	541		
Genetics	542	**S:** Erm, no not so much on my side, but on my, on ____(Father's	Family history of anxiety.
contributed to onset	543	Name) side I would say every member of his family suffers with	
	544	anxiety [nods].	
	545		
	546	**I:** Anxiety yeah. Erm, and do you think perhaps her personality might	
	547	have played any role?	
	548		
	549	**S:** Er yeah, yes I think so. She's very calm, she's got, erm, a brilliant	Hazel has lots of strengths/qualities – calm, attentive,
	550	attention span, she's, she listens really hard to everything. Yeah she	sensitive.
	551	doesn't miss anything you know and you think she totally hasn't	
	552	heard anything and she will say later [demonstrates Hazel talking and	
	553	laughs] and you will be like alright. Erm, I think she's erm, I think	
	554	she's quite sensitive, erm yeah [nods].	
	555		
	556	**I:** Ok, so is she quite bright?	
	557		
	558	**S:** I, I think she is, yeah I feel like she is. I mean you know how you	Hazel is "switched on" – bright.
	559	measure that I don't know, but she seems pretty switched on to me, I	
	560		

	561	don't, not necessarily in an academic sense, but I think, and she's	
	562	quite creative yeah.	
	563		
	564	**I:** Wow ok. And has she ever had any speech and language	
	565	difficulties?	
	566		
	567	**S:** No [shakes head], her, her, her language and her speaking has	No speech and language difficulties.
	568	always been really good and clear and quite early, yeah.	
	569		
	570	**I:** Brilliant, ok. And in terms of, erm, the impact of Hazel's Selective	
	571	Mutism, what do you think the key impacts have been for her?	
	572		*Very hesitant in language i.e. lots of pauses* – Perhaps as so
Impact on the child's social experience	573	**S:** Erm….(pause)….ohh gosh, I think….(pause)…. it's just really	many implications? Is it overwhelming? Doesn't know where
	574	meant that she has been very delayed in being able to make	the start?
	575	friendships with people, erm, and….(pause)…. because it's just been	
	576	too much for her. Erm, and yeah and learning as well, like I think	Delayed in building friendships. SM has acted has a barrier to
Impact on the child's education	577	she's, she's probably not a brilliant reader, but [emphasis on word] I	Hazel making friends.
	578	think she is far less good at it than she would be if she was more	
	579	confident, because she's, even when she reads with me, she, she can	SM has had a detrimental impact on Hazel's learning i.e.
	580	get a bit nervous about just saying, like she's, she's so worried about	reading – made it difficult for Hazel to access learning.
	581	getting it wrong that she doesn't want to try sometimes I think. Erm,	
	582	and she's the same with writing, she's, she can't, I think just the idea	Lack of confidence. Worries about getting things wrong - this
	583	of, I think she gets really frozen with anxiety at school if they say you	makes her not want to try sometimes. Lack of confidence acts
	584	have to you know make up a story, she just, she just can't [shakes	as a barrier to Hazel's learning.
	585	head], like I think [puts hand down over face] she just freezes and	
	586	yeah.	Freeze response. Anxiety causes Hazel to freeze at school.
	587		Freeze response acts as a barrier to Hazel completing
	588	**I:** Yeah, so do you think there is almost an element of things having	tasks/engaging in learning.
	589	to be perfect for her so she's not told off or?	Detrimental Impact on the child's education skills and access
	590		to learning.
	591	**S:** Yeah I think so and she's very like very [emphasis on word] rule	Rule abiding – rigid. Is being in a control a way of Hazel
	592	abiding, erm, I mean god now I've got another one, she's like, she	managing her anxiety?

Impact on the child's education	593 594 595 596 597 598 599 600 601 602 603 604 605 606 607 608 609 610 611 612 613 614 615 616 617 618 619 620 621 622 623 624	will do whatever she wants [laughs], erm I'm really seeing the differences between them. Erm, but yes Hazel's very, she wouldn't ever do anything naughty [shakes head], she, erm, she, she wants. She even said to me, bless her, she said "oh Mummy I just always want to impress you", erm, and I thought oh god [sad facial expression and rolls eyes], I was like you always do impress me, you're the bravest person I know you just, just by going out and going to school every day you impress me so much and blah blah, but yes she's very [nods] I think yeah. **I:** Ok, ok [nods]. And have school reported any concerns about the impact of her not being able to talk in lessons, like reading to the teacher? **S:** Yeah, well she doesn't read to the teacher [shakes head], so they haven't really been able to assess her reading level properly, so we recently done a video of her reading at home just so they can see where she might be. Erm, and they did like when she went from Reception to year one and they have to say whether they have achieved the, I can't remember what they are called now, but they said she hadn't got to whatever level it was. And they and actually her Reception teacher said, she said "I just don't think it would be fair for me to say that she has, because I think she needs more support to get there" and she, she said "you know I think it's because, it's because of her anxiety, it's also because we can't assess it properly, because she can't speak". **I:** Yeah. Was that kind of phonics and things like that they were meaning? **S:** Yeah, yeah.	Second child will do whatever – different to Hazel. Second child is easier to parent. Wouldn't do anything naughty. Perfectionist. Personality plays a role? Said wants to impress Mother. *Mother uses the phrase "oh god"* – shocked that her daughter thinks like that? Believes her daughter is brave. Doesn't read to the teacher. Teachers unable to assess and track her reading progress. Impact on the child's education . Videoed her reading at home. Teachers are creative and adaptable? Behind in her reading. Teacher believes that anxiety is a big barrier to Hazel's learning. Can't assess properly due to SM. SM is a barrier to assessing skills and tracking academic progress, which then makes it difficult to implement the right level of support.

	625 626 627 628 629 630 631 632 633 634 635 636 637 638 639 640 641 642 643 644 645 646 647 648 649 650 651 652 653 654 655 656	**I:** Yeah, so I think it's year one they do their phonics test isn't it? **S:** God I don't even know [laughs]. **I:** I think, unless, they might have done it in Reception, that might have been what she was mentioning may be. **S:** Oh may be. Actually she called it, oh god I'm sorry I keep doing this. **I:** No, it's alright [smiles]. **S:** G, oh it was GAD or something like that or. **I:** Oh ok. **S:** I'm just making up letters [laughs]. **I:** And I guess, erm, sort of across the Early Years curriculum, do you know if she kind of achieved the expected levels across the curriculum there, like in nursery**?** **S:** Erm, oh I don't know actually, erm, I can't really remember them talking about that from pre-school. **I:** Ok and did she, did she talk in nursery? **S:** No [shakes head], she, well actually it was the other way, so now she's, she finds it easier to speak to children than to adults, but in pre-school it was like adults and not children. Erm, and there was only really one adult, her key keyworker, who she just kind of followed around basically [nods].	Didn't speak in nursery. Early onset.

	657		
	658	**I:** Ok and did they, did nursery staff pick up on that it might be	Nursery staff didn't pick up that Hazel may have SM. Lack of
	659	Selective Mutism?	understanding. lack of early recognition.
	660		Mother wishes nursery staff would have picked up on it.
	661	**S:** [Shakes head] no. Because actually, actually three of them are ex	
	662	teachers as well so I often think oh I wish they, I wish they had, but	
	663	you know.	
	664		
	665	**I:** Yeah, ok. And I think may be it's just the lack of awareness	
	666	potentially.	
	667		
	668	**S:** Yeah, yeah absolutely.	
	669		
	670	**I:** Ok and in terms of sort of the emotional impact, has it impacted on	
	671	her confidence do you think?	Detrimental impact on child's emotional wellbeing, including
	672		her confidence.
Peer acceptance and	673	**S:** Yeah, I think it has and you know there's quite a lot situations now	
inclusion	674	where there's, mostly the kids in her class are just lovely and like	Enjoying the smaller class size (i.e. 7 of them). Smaller class
	675	she's gone back one day a week now, erm, and she's actually doing	size is *"perfect for SM"*. Positive impact on Covid-19
	676	really, she's really enjoying it [smiles], but I think that's 'cause	lockdown.
Positive impact of	677	there's only seven of them and it's perfect for SM [laughs]. This	
Covid-19 lockdown	678	whole set up now, it's like you know they can't mix with anyone else	School chosen Hazel's bubble very carefully. School staff are
	679	and it's one teacher, it's like oh brilliant. Erm, but, erm, yes so and	caring and want to help. School staff tried to ensure that Hazel
Peer acceptance and	680	like the little pod of children that they've put her with now are just,	was surrounded by peers who don't expect her to speak and
inclusion	681	they have chosen really carefully, and they're lovely and they're the	don't act surprised when she does speak. *Describes these*
	682	kind of kids who will always go "hi Hazel, hi Hazel" and there's is	*peers as "lovely"* – Some peers are supportive.
	683	no expectation for her to speak, but if she does they don't make a big	
	684	fuss about it, so that's perfect. But there are a few like little boys in	Some peers are less understanding i.e. will make a big deal
	685	her class who will, if she does speak, will say "oh Hazel, that's the	out of Hazel speaking causing unwanted attention. Lack of
	686	first time I've ever heard Hazel speak" and things, and she goes, and	understanding by some peers. This then discourages Hazel
	687	she will say to me "and it's not, they have heard me before" [upset	from speaking. Some peer reactions are unhelpful and perhaps
	688	tone of voice], but you know that's become a bit of, erm, and so then	exacerbated her anxiety?

Appendix K: The Process of Clustering Emergent Themes to Identify Superordinate Themes

Clustering Emergent Themes from Transcript One (Anna)

Early onset **First identified by nursery** **Recent diagnosis** **Diagnosed by SLT (NHS)** **Different child at home** **'Shut down' as self-protection** **SM has been enduring** **Difficulty settling into nursery** **Pulled out of nursery** **The power of animals** **Diagnosis of ASD** **High anxiety** **Connected to ASD** **Attended SM training** **Uncertainty about cause** **Early separation anxiety** **Not due to shyness** **Seeks reassurance from Mother** **Mother acts as a secure base** **Family history of ASD played a role** **Positive impact of Covid-19 lockdown - relief from anxiety**	**Good speech and language skills** **Difficulty accessing diagnosis** **Straightforward assessment procedure** **Gradual progress** **Attended specialist nursery (part of EHC assessment)** **Positive experience of specialist nursery** **Promoting independence** **Nursery staff lacked understanding** **Nursery staff had received training** **Blossoming since leaving nursery** **Reducing pressure** **Lack of collaboration** **Relieved to remove daughter from nursery** **Humour as a coping mechanism** **Training was enjoyable** **Resilient** **No impact on relationships with wider family**	**Nursery staff agreed with SM diagnosis** **Input from specialist teacher** **Lack of staff training** **Time as a barrier to training** **Nursery staff exacerbated child's anxiety** **Anti-anxiety medication** **Lack of adaptability** **Ongoing available advice from SLT** **Greater understanding in specialist nursery** **Need support with transition** **Hopeful about specialist setting** **Mother highly determined** **Child anxious about transition to school** **Pushed for diagnostic assessment** **Training helped parent to identify and implement strategies**	**Have to persist to get support** **Concerned about other parents** **Networking with other parents** **Access to parent support group for SM** **Leaflets are helpful** **Being the expert is sometimes a burden** **Hypervigilant when accessing online support groups** **Need to keep learning** **Training helped parent to identify and implement strategies** **Need to target SM in natural environment** **Need for greater knowledge** **Desire for daughter to have a friend** **Desire for daughter to be confident**

Impact on social relationships **Impact on learning** **Impact on physical wellbeing** **Impact on child's emotional wellbeing** **Impact on sibling** **Impact on mother's emotional wellbeing** **Emotional strain on Mother** **Frustrated with nursery staff** **Preparing in advance for meetings** **Drawing upon professional background** **Positive experience of childminder** **SM training was a game changer** **Lack of understanding** **Covid-19 lockdown** **Lack of professional awareness of SM** **Lack of available professional input** **Professionals not seeing the urgency**	**Self-referred for assessment** **Mother educating others** **Mother implementing strategies** **Self-seeking training** **Fighting for social inclusion** **Failed to implement appropriate support** **Working as a team with partner** **Firm approach** **Uncertainty about the cause**

PP 1 - Anna

Onset

- Early onset
- Uncertainty about the cause

What has Helped the Child

- Dedicated childminder
- The power of animals

What has Helped the Parent

- Social networking
- Training and advice from SLT

Impact on the Child and Parent

- Impact on the child's education
- Impact on the child's social interaction and relationships
- Impact on the child's physical wellbeing
- Impact on the child's emotional wellbeing
- Impact on the mother's emotional wellbeing

Barriers to Supporting the Child and Parent

- Lack of understanding
- Lack of collaboration
- Lack of commitment to intervention and inclusion

Taking on the Role of an Advocate

- Mother fighting for assessment and support

Clustering Emergent Themes from Transcript Three (Vicky)

Mother educating herself and others **Lack of concern by nursery staff i.e. downplayed anxiety (previous nursery)** **Early onset** **Difficulty participating in group learning** **Lack of intervention from professionals (i.e. SLT)** **Waiting lists** **Struggle to show true personality** **More comfortable around children than adults** **Gradual progress** **Dedicated keyworker acting as a secure base** **Mother self-referred for assessment** **Diagnosis provided clarity** **Lack of understanding** **Providing an accessible explanation to people in the wider community** **SM is not due to shyness**	**SM caused by anxiety and freeze response** **SLT provided initial information** **Parent educating others** **Detrimental impact of Covid-19 lockdown** **Supportive maternal grandparents** **Patient approach is helpful** **Mother exploring support options** **Mother suggesting support strategies to staff** **Mother delivering intervention strategies herself** **Family history of anxiety and SM** **Mother's intuition/gut feeling** **Dream baby** **Well behaved** **Can meet self-care needs** **Impact on everyday family life** **Adapting parenting approach** **Understands social norms** **Emotional strain on Mother**	**Personality played a role (i.e. fearful, perfectionism, sensitive)** **Impact on parenting approach** **Developed speech outside nursery** **Difficulty settling into nursery** **Learnt from previous nursery experience** **Larger provision was unhelpful** **SENCo educated staff (current nursery)** **Impact on social interaction and relationships (with peers and family)** **Concerned that SM may have greater impact in the future** **Academic learning is not a current priority** **Concerned about how daughter will cope in school** **Mother scaffolding social relationships (i.e. other children, grandparents)**	**Baby sister is a source of support (i.e. helping to build confidence)** **Nursery staff are understanding and accommodating (current nursery)** **Mother helping daughter to move on from previous negative experiences** **Lack of SM training** **Uncertain about how SENCo accessed further knowledge** **Lack of adaptations to communication (i.e. visuals)** **Nursery keep parent in the loop** **Can engage in learning more easily away from others** **Smaller provision is helpful** **Parent left in the dark in terms of available support** **Desire for more structured guidance and support** **Mother chasing referral**

Hopeful outlook **Concerned about accessing support in the future** **Relieved about early recognition** **Mother self-educating** **Being proactive** **Desire for professionals to be knowledgeable of SM** **Desire for professionals to be transparent about whether they specialise in SM** **Supportive partner** **Preparing for the future** **Familiarity helps** **Preparing for the future** **Impact on child's emotional wellbeing** **Genetics contributed to onset** **Impact on child's education** **Impact on mother's parenting approach**	**Impact on child's social interaction and relationships** **Dedicated keyworker** **Nursery staff are accommodating** **SENCo educating staff** **Negative impact of Covid-19 lockdown** **Clearer guidance and support** **Professionals to be transparent** **Mother seeking support** **Support from partner** **Accommodating nursery staff** **Nature and nurture**

PP 3 - Vicky

Onset

- Early onset
- Nature and nurture

Supportive Nursery

- Dedicated keyworker
- Accommodating nursery staff

What has Helped the Parent

- Acceptance and preparation

Impact on the Child and Parent

- Impact on the child's emotional wellbeing
- Impact on the child's education
- Impact on the child's social interaction and relationships

Barriers to Supporting the Child

- Lack of understanding
- Parent left in the dark in terms of available support

Improvements to Support for the Child and Parent

- Clearer guidance and support

Taking on the Role of an Advocate

- Mother fighting for support

Appendix L: Table of Superordinate and Subordinate Themes for Participant One

Table of Superordinate Themes and Subordinate Themes – PP 1 ANNA		
Themes **Superordinate theme** Subordinate theme	**Page/Line Numbers**	**Key Words**
1. Onset		
• Uncertainty about the cause	10/267 11/284 13/335 13/346	No idea, no traumatic experiences I don't know Autism, can't be certain Travelled back, nothing
2. Impact on the Child and Parent		
• Impact on the child's emotional wellbeing	4/71 16/460 17/476 20/589 23/684 35/1035 44/1328 50/1540	Sleeping, crying out Shut down, sadness Terrified Confidence and self-esteem are incredibly low Wasn't happy Screaming, burst into tears, anti-anxiety medication Pressure, crumbled, anxious Lack of confidence
• Impact on the child's social interaction and relationships	16/451 17/474 17/488 18/501	Hasn't got friends, never been able to make friends Let's brother lead, can't make that step Took a year with Nan, shut down, long time Won't speak to other family members

	50/1545 60/1849	Girl laughed and run away Want her to have a friend, play dates
• Impact on the child's education	19/535 19/551 21/608 21/616	Shocking levels, rubbish, crazy, really clever Low levels, not reflective of ability Wouldn't take coat off, shut down, look down Just stand there
• Impact on the child's physical wellbeing	23/664 23/673 23/679	Wet herself or hold it, extreme pain Couldn't eat, knickers wet, tummy ache Tummy ache, barely eat, wasn't drinking
• Impact on the mother's emotional wellbeing	18/511 21/607 29/854 34/1009 51/1570 59/1825	Worried being rude, irritating Horrendous Stressed during run up to meetings Horrendous, really upsetting Want to rescue, take her out of situation, not nice Stress, desperate for help, annoying, crystal ball
3. What has Helped the Child		
• Dedicated childminder	4/94 4/102 22/642 24/690 24/699 24/705 25/723	Spoke Little niche, lovely, pleased Start to develop, coming out of herself Huge lunch, nothing left, bottles gone Whole lot was gone, wow, incredible Smaller provision, animals, no pressure, a lot calmer Listened, went along
• The power of animals	5/91 5/107 6/122 24/708	Spoke, loves animals, dog, dog walk, chatting away Always talks, chat, room full of people No pressure Dog, finds calming, three cats, animals, a lot calmer

4. Barriers to Supporting the Child and Parent		
• Lack of commitment to intervention and inclusion	22/631 31/919 31/936 32/967 35/1066 36/1070 36/1090 37/1107 38/1136 38/1136 38/1152 41/1249 44/1337 44/1348	Not doing what learnt Say all these things, sketchy answers, Identiplay, review meeting, no idea, no boards up Attention Autism, haven't used it, lying, ceased Non-direct, choice board, never happened WOW system, way to join in, never did Dark den, didn't do Turn-taking, broke the rules, car crash Sliding in, never hit a plan Worship, everyone goes Had to start going again Sounded like knew what they were doing, practice Choice board, easy stuff, just they didn't Do what you say
• Lack of understanding	9/226 10/245 18/525 21/612 24/622 33/995 33/1001 34/1003 37/1110 56/1734	Looking the same, Autism, difficult to separate Basic understanding Absolutely not Meant to have had training, don't do that Chose art, didn't get it Don't think understood Not all staff trained, one person, didn't have time Can't have own way, old school attitude Turn-taking, advanced plan, other children, car crash Wasn't something knew loads about
• Lack of collaboration	25/730 37/1118 37/1126	Weren't open to suggestions Turn taking, little while End up yelling, cross, not listening, frustrating
5. Taking on the Role of an Advocate		

• Mother fighting for assessment and support	46/1408 49/1503 57/1767	Make a difference, needs to be in EHCP Turned away, keep going, ringing, being annoying Bullet point, write a report, gets me
6. What has Helped the Parent		
• Social networking	52/1599 55/1690 56/1715 68/1791	Parent support groups, Facebook SMiRA Facebook group, be careful Face to face meetings, listen to other parents Parent network, get yourself out
• Training and advice from SLT	10/250 10/258 15/415 15/424 27/801 40/1205 47/1218 42/1273 45/1378 46/1403 47/1443 53/1632 56/1726 56/1734	Amazing, nodding Incredible, just everything, real moment Told me to refer, felt validated Like God More confident Regular emails, inviting, trained anytime, questions Any questions, no problem Getting support need SLTs name, all ears, said been on training course Would have turned me down Learnt how to be at home, helpful Email, suggestions, print outs Only with SLTs help, game changer Validated everything, confidence

Appendix M: Data Management Plan

UEL Data Management Plan: Full
For review and feedback please send to: researchdata@uel.ac.uk
If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).
Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Claire Douglas
PI/Researcher ID (e.g. ORCiD)	Student ID number: U1825073 ORCID ID number: https://orcid.org/0000-0003-0338-3345
PI/Researcher email	U1825073@uel.ac.uk
Research Title	What are the Lived Experiences of Parents' Understanding and Supporting their Child with Selective Mutism? An Exploratory Study.
Project ID	Ethics application number
Research Duration	Proposed end date April 2021
Research Description	• The research aims to explore the lived experiences of parents (or legal guardians) understanding and supporting their child with Selective Mutism (SM) due to a current lack of research in this field and the concerns identified through the researcher's background reading. This includes a lack of awareness and understanding of SM by school staff and other professionals, a delay between recognition and assessment and intervention, the detrimental impact of SM, and a lack of adequate provision and support for children and young people with SM and their families. This is inconsistent with national legislation and government initiatives to improve mental health support within schools. • The parents will be provided with the opportunity to share their unique views and experiences in order to answer the four following research questions:

	1. What are parents' experiences of what may have led to their child presenting with SM? 2. What are parents' experiences of the impact of SM? 3. What are parents' experiences of accessing support? 4. What are parents' experiences of coping with their child's SM? • The purpose of this research is to gain deeper insight into the cause and impact of SM and support that parents have been able to access (for example, from school staff and other professionals) to promote the wellbeing and inclusion of their child and what support they have found helpful. It will also shed light on how parents feel that they have coped with the phenomenon of SM. It is hoped that this will increase the awareness and understanding of SM by educational and health professionals and inform their practice, resulting in earlier identification and earlier and more effective support. This will fulfil the ultimate purpose of advocating for the equality and inclusion of CYP with SM, so that they are able to have a positive experience of education, live fulfilled lives, and reach their academic and social potential.
Funder	Does not apply to this research – part of professional doctorate
Grant Reference Number (Post-award)	Does not apply to this research
Date of first version (of DMP)	11/01/2020 (reviewed by Penelope Jackson)
Date of last update (of DMP)	18/01/2020 21/01/2020 11/02/2020 26/03/2020
Related Policies	UEL's Research Data Management Policy
Does this research follow on from previous research? If so, provide details	No
Data Collection	

What data will you collect or create?	• The research will focus on the parents (or legal guardians) accounts as opposed to gathering numerical or statistical data. Three to six parents (or legal guardians) will complete semi-structured interviews (with unstructured probes to promote a conversational-style) with open-ended questions, lasting between 30 and 40 minutes, in person or via Skype. The data will consist of the parents' responses to the open-ended interview questions. This will likely include some sensitive data (i.e. the gender and age of their child and co-morbid medical diagnoses). The parents' responses during the interview will be recorded by hand and audio recorded with a Dictaphone or via the record system on Skype. The hand written notes will be scanned and uploaded onto the researcher's personal password protected laptop saved as a .PDF or JPG. The hard copy will then be destroyed (shredded). The audio recordings (mp3 files [if from a Dictaphone] and mp4 files [if from Skype]) will also be uploaded and saved onto the researcher's personal password protected laptop. The recordings will be later transcribed verbatim into a typed Microsoft Word document by the researcher. • The interviews will result in approximately 2.4GB (with a likely maximum of 3GB) of audio data. • The researcher may use a qualitative data analysis software to help analyse the data i.e. if there is a large amount of data and the researcher is struggling for time (i.e. Nvivo). • The data will then be analysed and following this analysis, the researcher will again meet with each parent (or communicate with them via phone, email, or a free online telecommunications application, such as Skype) to go through the data and the researcher's interpretations to check with the parent that they accurately reflect their views (completing a member check). The researcher will take typed notes during their conversation with the parent and then amend the data based upon these notes. • Personal data about each parent (for example, their name, location, and address) will be collected via the consent letter and via email and phone prior to the interview via the researchers UEL email address (for the purpose of arranging the interview). • Each parent will be assigned a participant number (in chronological interview order i.e. "participant 1'") and a pseudonym. This number and pseudonym will be recorded

	at the top of the parent's transcript and at the top of the notes that the researcher makes when completing member checks. • All of the material and collected data will be pseudo anonymised. This means that the parents will be identifiable from the material (for example, the interview transcripts) and data collected by the researcher and the researcher only. The researcher will keep a list of the parents' names and contact details and a number will be placed next to the parents' names (email address or phone number only to minimise personal data stored) in a password protected Microsoft Word document (on an encrypted memory stick). The researcher will also keep a list of the numbers with corresponding pseudonyms (that have been assigned to each of the participants) in a password protected Microsoft Word document on their personal password protected laptop. This document will be backed up onto a separate encrypted memory stick or hard drive and onto the researcher's personal space on the UEL One Drive. All anonymised data collected during the research will also be saved in a separate folder to the Microsoft Word documents containing the participant numbers and corresponding pseudonyms (and backed up onto the encrypted memory stick or hard drive and UEL OneDrive where the document containing the participant numbers and pseudonyms will be stored). Ensuring that the participants can be identified by the researcher through looking back at the two Microsoft Word documents will be important in ensuring that the any material and data can be tracked to the participant, so that it can be destroyed as and when requested by the parents (unless the data has already reached the point of analysis). However, all material and data will be shared and presented to others (and included in the write up of the thesis) anonymously, including the researcher's research supervisor. Only the parent's participant number and pseudonym will be used. • All identifiable information, including the parent's real name and their contact details, the name of their child and their child's school, and the location (and local authority) of where they live and where their child attends school will be anonymised in the transcripts and in the notes that the researcher takes when completing the member checks.
How will the data be collected or created?	• The interviews will be conducted on a face-to-face individual basis in a quiet confidential space, ideally in a room in the school of the parent's child or in a room in the

	EPS office base where the researcher is currently completing a placement. If this is not possible, the researcher will arrange an alternative public location. For example, they may book a room in a children's centre. The researcher may also conduct interviews over the phone or via a free online telecommunications application, such as Skype. • The researcher will have a list of broad guiding interview questions (covering different topics), but may change the order of these questions and ask unplanned questions to follow up on what the parent has said or to prompt for further information. • The researcher will take notes during the interviews and the interviews will also be audio recorded on a Dictaphone or via the record system on Skype. The audio files will be later transcribed verbatim on a laptop as a Microsoft Word document by the researcher. These documents will be password protected and only the researcher will know the password. The researcher may also use a qualitative data analysis software, such as NVivo to assist with the analysis. • When the researcher meets face-to-face with each parent (or communicates with them via email, phone, or a free online telecommunications application, such as Skype) following the analysis of the data the researcher will take typed notes (on a Microsoft Word document on their personal laptop that only they have access to). This document will again be password protected and only the researcher will know the password.
Documentation and Metadata	
What documentation and metadata will accompany the data?	• Participant information and invitation letter • Participant consent letter • Letters confirming the diagnosis of the child • Participant debrief letter • A list or table of the participants personal details and corresponding participant numbers and pseudonyms • A set of broad interview questions that will act as a guide for the researcher. However, the research may also ask unplanned questions to prompt the parents to give further information, to further explore and understand an issue, and clarify any misunderstandings. • Written notes from the interviews.

	• Audio recordings and verbatim transcripts (from the interviews). It is estimated that the researcher will collect approximately 9 hours worth of audio recordings. • Typed notes in a Microsoft Word document when completing member checks (following analysis of the data) • A personal research diary maintained by the researcher (including anonymised material and data only)
Ethics and Intellectual Property	
How will you manage any ethical issues?	• The parents will first be provided with a typed information and invitation letter about the research that will enable them to make an informed decision about whether they wish to take part in the research. The researcher's contact details are presented at the bottom of the letter and the letter highlights that the parents should contact the researcher if they wish to volunteer to take part. Whenever a parent contacts the researcher, the researcher will confirm with the parent that they have read the information and invitation letter. If they have not read this letter, the researcher will email them a copy and ask them to read this carefully before deciding whether they wish to take part. • Once a parent has read the information and invitation letter they will be sent a consent letter to sign and email back to the researcher. Verbal consent will also be gained from the parents just before each interview. • The parents will be advised of their right to withdraw from the research at any point without explanation or consequence. They will also be advised of their right to request for any of their data to be destroyed, unless it has already reached the point of analysis (meaning that the researcher has already started to write comments on the transcript). At this point the researcher will still reserve the right to use the participant's anonymous data even if they have withdrawn from the research study. This is made clear to the parents on the information and invitation letter, consent letter, and debrief letter. In addition, the researcher will verbally explain the participant's right to withdraw just before each interview. • Transcription will be undertaken by the researcher to protect the participants identity. The researcher will pseudo anonymise each transcript, replacing the participants name with a pseudonym (which will be recorded in a password protected Microsoft Word document previously explained by this document).

	• All of the material and collected data will be pseudo anonymised. This means that the parents will be identifiable from the material and data collected by the researcher and the researcher only. All material and data will be shared and presented to others (and included in the write up) anonymously, including the researcher's research supervisor and second research supervisor. Only the parent's participant number and pseudonym will be used in the transcripts and in the notes that the researcher takes when completing member checks. Other identifiable information such as the parent's contact details, the Local Authority of where the parent lives, and the name of their child's school will be removed. The child's name will be replaced by a pseudonym. This will ensure confidentiality. • The parent's identity may be revealed if they assist with disseminating the findings (for example, co-presenting with the researcher at conferences). However, this is made clear to the parents in the information and invitation letter, consent, and debrief letter and additional written consent will be accessed. • In case of emotional distress during or following the interview, the researcher will ensure an empathetic approach and will explain to the parents that they can skip any questions that might be too distressing. The researcher will also use their professional judgement to recognise when a participant may need a break from the interview or is too distressed to continue with the interview and end the interview at this point. Furthermore, the parents will be provided with a debrief letter at the end of the interview, which contains a list of organisations where they may be able to access further advice or support. The debrief letter also contains a list of key texts that the parents and the children and young people themselves may find helpful in further understanding SM and highlights the importance of the parents speaking to the Special Educational Needs Coordinator at their child's school or to their child's General Practitioner (GP) if they are concerned about the wellbeing of their child. If the researcher becomes concerned about the emotional wellbeing or mental health of the parent (for example, if they appear highly distressed) they will also suggest that the parent speaks to their own GP. Finally, the researcher will seek further advice from their research tutor or fieldwork tutor on placement if they are overly concerned about a parent or their child.

How will you manage copyright and Intellectual Property Rights issues?	Does not apply to this research project.
Storage and Backup	
How will the data be stored and backed up during the research?	• Signed consent letters will be directly downloaded from the researcher's UEL email account and saved (in a .PDF format) onto an encrypted memory stick. Only the researcher has access to this memory stick. The email will then be immediately deleted. The letters will be saved in a separate folder to documents containing any other information about the participants. Alternatively, if the parents give the researcher a hard signed copy of the consent letter, the researcher will scan, upload, and save the consent letter (in a .PDF format) onto the encrypted memory stick. The physical letter will then be placed in the confidential waste bin at the researcher's current placement in an Educational Psychology Service. • Letters confirming the diagnosis of the child will be directly downloaded from the researcher's UEL email account and saved (in a .PDF format) onto an encrypted memory stick. Only the researcher has access to this memory stick. The email will then be immediately deleted. The letters will be saved in a separate folder to documents containing any other information about the participants. Alternatively, if the parents give the researcher a hard signed copy of the consent letter, the researcher will scan, upload, and save the consent letter (in a .PDF format) onto the encrypted memory stick. The physical letter will then be placed in the confidential waste bin at the researcher's current placement in an Educational Psychology Service. • The parent's personal information (including their name and contact details) will be saved onto a password protected Word document (and only the researcher will know the password) on an encrypted memory stick. Only the researcher has access to this memory stick. This document will be saved in a separate folder to the consent forms. • Hard copies of any written information taken during the interviews will be scanned, uploaded, and saved (in a .PDF format) onto the researcher's password protected laptop immediately after the interview. The physical copy will then be placed in the confidential waste bin at the researcher's

	current placement in an Educational Psychology Service. The written information will be stored electronically in a separate folder to the audio recordings and transcripts. • Audio recordings of the interviews will be uploaded from an unencrypted Dictaphone onto the researcher's laptop immediately after the interviews. Once the audio recordings have been uploaded onto the laptop, the audio recordings will be deleted from the Dictaphone. The audio recordings will then be transferred onto and stored on an encrypted memory stick or hard drive and deleted off the laptop. This will be a separate memory stick or hard drive to where the transcripts are stored. Alternatively, if Skype is used the audio recordings will be directly saved onto a file on the researcher's laptop. These files will then be transferred onto and stored on an encrypted memory stick or hard drive (and the UEL OneDrive) and deleted off the laptop. • The audio recordings will be transcribed by the researcher only and stored as .docx files on an encrypted memory stick or hard drive (separately to the transcripts). • The transcripts and the notes that the researcher will take when confirming their interpretations with the parents will be stored as .Word files on the researcher's password protected laptop. • The researcher's personal research diary will be stored as a Microsoft Word document on the researcher's personal password protected laptop. Only the researcher will know the password. All personal identifying information about the participants will be removed and pseudonyms will be used for the parents and their children. • The Microsoft Word document containing the participant's names and contact details will be backed up weekly onto an encrypted memory stick or hard drive (separate to the encrypted memory stick or hard drive where the rest of the data will be stored). • All other files and documents, including the Microsoft Word document with the participant numbers and corresponding pseudonyms, audio files, transcripts, and personal research diary will be backed up daily to an encrypted memory stick or external hard drive that only the researcher has access to and to the researcher's personal area on the UEL OneDrive.

	• Each audio file will be named with the participant's initials and then the date of the interview (for example, "AN 10/07/2019"). Each parent will be assigned a participant number (in chronological interview order i.e. "participant 1") and a pseudonym. The transcription files will be named according to the parent's participant number and pseudonym (for example, "participant 1 Rosie"). • All materials and data will be erased from the researcher's personal area on the UEL OneDrive once they have graduated. Data will continue to be stored on the researcher's personal laptop and encrypted memory sticks or hard drives for a maximum of five years once the researcher's thesis has be examined and passed. This will allow time for publication and dissemination. All materials and data will be then be deleted.
How will you manage access and security?	• Audio recordings of the interviews will be uploaded from an unencrypted Dictaphone onto the researcher's laptop immediately after the interviews. Once the audio recordings have been uploaded onto the laptop, the audio recordings will be deleted from the Dictaphone. The audio recordings will then be transferred onto and stored on an encrypted memory stick or hard drive and deleted off the laptop. This will be a separate memory stick or hard drive to where the transcripts are stored. Alternatively, if Skype is used the audio recordings will be directly saved onto a file on the researcher's laptop. These files will then be transferred onto and stored on an encrypted memory stick or hard drive (and backed up on the UEL OneDrive) and deleted from the Skype application. • The researcher will transcribe all of the interviews and will remove any identifiable information during this process. • During the research process the researcher will share the anonymised transcripts with their research supervisor (and their second research supervisor and other members of the tutor team if necessary) in a secure manner (via UEL email). The researcher may also share transcripts with thesis examiners and the participants at the member check stage. However, each participant will only have access to their own transcript. • The anonymised transcripts will not be shared with other students or professionals due to the likely sensitive nature of the data and to promote confidentiality.

	• All portable encrypted storage devices will be stored in a locked cupboard or draw on the researcher's property.
Data Sharing	
How will you share the data?	• The researcher will share the anonymised transcripts with their research supervisor (and possibly their second research supervisor and other members of the course tutor team and thesis examiners) via UEL email throughout the research process. The file names will consist of a participant number and pseudonym (for example, "participant 1 Rosie"). • Extracts of the transcripts will be provided in the final write up of the research and in any subsequent publications. They will also be included when disseminating the findings through other means, for example, at conferences. All identifiable information will be anonymised. However, if the parents assist with this dissemination (for example, co-present with the researcher at a conference) it is possible that their identity may be revealed. However, this assistance is optional and additional written consent will be gained in advance of this. • The anonymised transcripts will not be deposited on the UEL repository due to the likely sensitive nature of the data and to promote confidentiality.
Are any restrictions on data sharing required?	• Personal information about the participants will not be shared. This information will be destroyed five years after the researcher has passed their thesis. • The anonymised transcripts will not be made available to other students and researchers (via the UEL repository) due to the likely sensitive nature of the data and to promote confidentiality. • The audio recordings may be shared with the researcher's first and second research supervisors and the thesis examiners, but only if formally requested. The recordings will not be shared with anyone else.
Selection and Preservation	

Which data are of long-term value and should be retained, shared, and/or preserved?	• Copies of the consent letters and letters confirming the child's diagnosis will be immediately destroyed once the researcher has passed their thesis. However, the researcher will continue to store the remaining material and data (on their personal password protected laptop and encrypted external memory stick or hard drive) for a maximum of five years to allow time for publication and dissemination, including the interview transcripts. The contact details and names of the participants will also be stored for up to five years (on a separate encrypted memory stick or hard drive), so that they can be invited to assist with disseminating the findings, for example, at conferences.
What is the long-term preservation plan for the data?	• All of the material and data (other than the consent forms and letters confirming the child's diagnosis) will be stored on a password protected laptop that only the researcher has access to, for five years. This will include all of the interview recordings and transcripts. The contact details and names of the participants will also be stored, so that they can be invited to assist with disseminating the findings. After the five years the participants personal details, alongside all of the material and data collected (including the interview recordings and transcripts), will be destroyed. • All of the material and data will be deleted off the OneDrive once the researcher graduates as the researcher will lose access to this drive. All of the material and data (other than the Microsoft Word document containing the participants names and contact details) will remain on an encrypted memory stick or hard drive for the five year period. • The Microsoft Word document containing the participant's names and contact details will remain on a separate encrypted memory stick or hard drive for the five year period.
Responsibilities and Resources	
Who will be responsible for data management?	The researcher.
What resources will you require to deliver your plan?	Access to a password protected laptop, a secure cloud system (the researcher's personal space on the UEL OneDrive) licenced by the University of East London, and an encrypted memory stick or external hard drive.

Review	**Ensure portable devices are kept in lockable storage** **Audio recordings and transcripts to be stored separately after the research has ended**
This DMP has been reviewed by: Date: 21/10/2020 Updated 11/02/2020 Updated 26/03/2020	Penny Jackson
	Signature: Penny Jackson Research Data Management Officer

Guidance
Brief information to help answer each section is below. Aim to be specific and concise.
For assistance in writing your data management plan, or with research data management more generally, please contact: **researchdata@uel.ac.uk**

Administrative Data
Related Policies
List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

Data collection
Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

Documentation and Metadata
What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

Ethics and Intellectual Property
Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

Storage and Backup
Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

Data Sharing
Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository (data.uel.ac.uk) or a subject repository. How long should data be retained?

Appendix N: Two Extracts of Research Diary

Diary Extract One

Date:
22/06/2020
Activities Completed and Purpose (i.e. collected data, had supervision with research tutor)
• Interviewed participant 6 over Skype.
Outcome
• The interview lasted 1 hour 45 minutes
Reflections (i.e. my feelings, what I learnt, how myself and my feelings/values might be impacting on the research findings)
• This was the longest interview I have completed. I feel that this was partly related to how open the parent was to sharing her experiences, views, and feelings and how keen she was to share, and the fact that I did not want to disrupt the flow of the conversation by interrupting the parent. Interrupting the parent may have also reduced the level of empowerment experienced by the parent. However, the length of the interview may have also been related to my unconscious desire to gain as much information as possible with my understanding that it would likely be my last interview (and last chance to gain insight directly from the parent). • I really respected the parent's ability to speak so openly and honestly about her feelings. It was a great privileged to be let into the parent's world and to step into her shoes for a short amount of time. This enabled me to really experience and understand both the pain and joy that the parent had felt at different time points in supporting her daughter. • This interview again made me feel quite emotional as the mother referred to difficulties experienced by her daughter that I could really resonate with (due to my own experience of SM). The parent also became quite tearful when discussing her own anxiety and how she had started taking antidepressants. • Having my own personal experience of anxiety and SM and sharing this with the parent (to a certain extent) seemed to really help the parent to feel heard and understood. There was a lot of back and forth sharing, perhaps too much? I am not sure, but it seemed to really promote our rapport so I think that the benefits of doing so definitely outweighed any of the potential limitations. I also felt that, despite sharing some of my own experiences, I maintained a neutral position, asking open-ended questions in a non-judgemental manner and then clarifying information to ensure that I understood the mother's experience properly. I do not feel that there was any obvious bias as a result of a lot of sharing (from myself). Having my own experience of anxiety and SM actually seemed to really help me to understand the mother instead, which I believe will result in more accurate data and interpretations. • Following the interview I felt really passionate about trying to make a difference for parents of children with anxiety disorders, such as SM. For example, by setting up a parent support group in the future (once I qualify as an EP). I feel quite driven to do this on the basis of most of the PPs (if not all) commenting that such groups currently do not exist and would offer them a great deal of emotional support. Overall, this interview has fired up my passion for promoting the best outcomes for children with SM even more.
Action Points (if any)
• To keep in mind how most of the parents have highlighted how they may benefit from attending parent support groups (specifically for SM) when interpreting and analysing the interview data.

Diary Extract Two

Date:

01/08/2020

Activities Completed and Purpose (i.e. collected data, had supervision with research tutor)

- Completed first analysis (for PP 2 - interview 2)

Outcome

- The process took 5 whole days.

Reflections (i.e. my feelings, what I learnt, how myself and my feelings/values might be impacting on the research findings)

Stage 1: Re-reading the transcript

- I had already re-read the transcript at least three times as part of the transcription process to ensure that the transcription was accurate. I am glad that I did this as I already felt like I had gained some good insight into the participant's experiences and almost felt like I knew the participant. However, to ensure that the participant was at the forefront of my mind (and to bracket off the insight I had also gained through transcribing the interviews for the other participants) I decided to read the transcript one more time.

Stage 2: Exploratory comments

- I found making initial notes quite daunting. I almost felt like I didn't really know what I was doing. I think this was due to it being my first time using IPA. I am a complete novice to IPA, previously tending to use thematic analysis in my research. I was particularly worried about missing important interpretations and perhaps making interpretations based upon my own biased assumptions as opposed to the participant's actual experiences. To promote my confidence I made detailed notes on each stage of IPA, including the stage of making initial notes (exploratory comments), using the Smith et al (2009) book. I also explored examples through accessing research papers completed by previous Trainee EPs and Trainee Clinical Psychologists. This gave me a better idea of how in depth the comments should be and was, therefore, very helpful.
- This stage took longer than I had initially anticipated. I had planned to use one day, but it actually took me just over two days. I felt very anxious on day one, but seemed to get into the swing of things on day two. On day 2 I felt much more confident and actually enjoyed the process.
- I am wondering if my notes are too comprehensive and I am slightly worried about time as I still have five more interviews to analyse. However, I am happy with how comprehensive my notes are, as I believe that this will make further stages of the IPA process easier. I am also hoping that as I become more experienced and confident each stage will start to take less time.
- Overall, I am proud of myself for getting to the end of this stage.

Stage 3: Emergent themes

- As I moved into two stage I again initially felt anxious (similar to the start of stage 2). I felt a little out of my depth and was concerned about picking out the 'wrong' emergent themes. I am not sure if picking out the 'wrong' themes is even possible, but that was the root of my anxiety. I guess I was also preoccupied with trying to do the participant justice. I really wanted to ensure that the emergent themes closely reflected their views. I again found it helpful to look at my notes from the Smith et al (2009) book and to look at other people's thesis papers.
- This took me two half days, which was within the timeframe I had predicted.

Stage 4: Searching for connections across emergent themes (superordinate and subordinate themes)

- This stage was probably the most challenging. I seemed to have a lot of emergent themes (around 100) to group and felt quite overwhelmed when I had printed the themes out and laid them out onto the table. There just seemed too many. However, through reading my notes from the Smith et al (2009) book I was reminded that not all my emergent themes may be relevant to my research questions and that some emergent themes can be disregarded at this stage. I therefore printed out my research questions and put these in front of me to help me to remove any themes which did not seem relevant. My research questions seemed to act as a framework. I also reminded myself of the psychological theories underpinning my research. Following this process, the idea of grouping the themes felt much more manageable.
- I am glad that I took the traditional approach of printing off the emergent themes and then grouping them by hand. It meant that I could quickly scan between the emergent themes and keep moving themes around in an effortless manner.
- I found identifying each group of subordinate themes quite straightforward, but found identifying appropriate superordinate themes very challenging. For many of the groups of subordinate themes, I found it difficult to identify a theme/label that would adequality cover all those themes. I ended up brainstorming different possibilities with the use of a thesaurus and talking through the different possibilities with my partner, which I found really helpful in supporting my thinking. I then waited until the next day (to ensure that I had a fresh mind) to present and organise my superordinate and subordinate themes in a table. With a fresh mind I decided to combine and lose and rename some subordinate themes.
- By the end of this stage I felt a big sense of relief and felt very proud of my ability to persist with such a novel form of analysis. Putting my feelings of anxiety and stress to one side, it was also a very enjoyable process. I am hoping that I feel less anxious when analysing the remaining interviews so that I can full immerse myself and just enjoy the process.

Action Points (if any)

- I will now share my superordinate and subordinate themes with my research supervisor and ask for their opinion on whether the themes seem appropriate. I am hoping that this will reassure me that I am on the right track in terms of using IPA. This may then increase my confidence before moving onto the next interview.
- Once I have spoken to my supervisor I will move onto analysing the first interview, which is slightly longer and more complex. I think it's better to gain a little more experience and confidence before I analyse the longer and more complex interviews (i.e. interview 6).
- When analysing the next interview I will pay greater attention to my emergent themes, ensuring that I have a more concise list with terms that I feel best represent the participant's experiences. This will then help me to identify superordinate themes.

Appendix O: All Superordinate and Subordinate Themes for Each Participant

Table O1

Anna's Themes

Table of all Superordinate Themes and Subordinate Themes for PP 1 (Anna)		
Themes **Superordinate theme** Subordinate theme	**Page/Line Numbers**	**Key Words**
1. Onset		
• Uncertainty about the cause	10/267 11/284 13/335 13/346	No idea, no traumatic experiences I don't know Autism, can't be certain Travelled back, nothing
2. Impact on the Child and Parent		
• Impact on the child's emotional wellbeing	4/71 16/460 17/476 20/589 23/684 35/1035 44/1328 50/1540	Sleeping, crying out Shut down, sadness Terrified Confidence and self-esteem are incredibly low Wasn't happy Screaming, burst into tears, anti-anxiety medication Pressure, crumbled, anxious Lack of confidence

• Impact on child's social interaction and relationships	16/451 17/474 17/488 18/501 50/1545 60/1849	Hasn't got friends, never been able to make friends Let's brother lead, can't make that step Took a year with Nan, shut down, long time Won't speak to other family members Girl laughed and run away Want her to have a friend, play dates
• Impact on the child's education	19/535 19/551 21/608 21/616	Shocking levels, rubbish, crazy, really clever Low levels, not reflective of ability Wouldn't take coat off, shut down, look down Just stand there
• Impact on the child's physical wellbeing	23/664 23/673 23/679	Wet herself or hold it, extreme pain Couldn't eat, knickers wet, tummy ache Tummy ache, barely eat, wasn't drinking
• Impact on the mother's emotional wellbeing	18/511 21/607 29/854 34/1009 51/1570 59/1825	Worried being rude, irritating Horrendous Stressed during run up to meetings Horrendous, really upsetting Want to rescue, take her out of situation, not nice Stress, desperate for help, annoying, crystal ball
3. What has Helped the Child		
• Dedicated childminder	5/94 5/102 22/642 24/690 24/699 24/705 25/723	Spoke Little niche, lovely, pleased Start to develop, coming out of herself Huge lunch, nothing left, bottles gone Whole lot was gone, wow, incredible Smaller provision, animals, no pressure, a lot calmer Listened, went along
• The power of animals	5/91	Spoke, loves animals, dog, dog walk, chatting away

	5/107 6/122 24/708	Always talks, chat, room full of people No pressure Dog, finds calming, three cats, animals, a lot calmer
4. Barriers to Supporting the Child and Parent		
• Lack of commitment to intervention and inclusion	22/631 31/919 31/936 32/967 35/1066 36/1070 36/1090 37/1107 38/1136 38/1136 38/1152 41/1249 44/1337 44/1348	Not doing what learnt Say all these things, sketchy answers, Identiplay, review meeting, no idea, no boards up Attention Autism, haven't used it, lying, ceased Non-direct, choice board, never happened WOW system, way to join in, never did Dark den, didn't do Turn-taking, broke the rules, car crash Sliding in, never hit a plan Worship, everyone goes Had to start going again Sounded like knew what they were doing, practice Choice board, easy stuff, just they didn't Do what you say
• Lack of understanding	9/226 10/245 18/525 21/612 24/622 33/995 33/1001 34/1003 37/1110 56/1734	Looking the same, Autism, difficult to separate Basic understanding Absolutely not Meant to have had training, don't do that Chose art, didn't get it Don't think understood Not all staff trained, one person, didn't have time Can't have own way, old school attitude Turn-taking, advanced plan, other children, car crash Wasn't something knew loads about

• Lack of collaboration	25/730 37/1118 37/1126	Weren't open to suggestions Turn taking, little while End up yelling, cross, not listening, frustrating
5. Taking on the Role of an Advocate		
• Mother fighting for assessment and support	17/510 27/852 53/1658 54/1698 57/1807 67/2123	Not got through, rang, triage, hadn't looked properly Don't pressure, don't ask questions Go away on its own, "don't think so, do you?" Make a difference, needs to be in EHCP Turned away, keep going, ringing, being annoying Bullet point, write a report, gets me through
6. What has Helped the Parent		
• Social networking	52/1599 55/1690 56/1715 68/1791	Parent support groups, Facebook SMiRA Facebook group, be careful Face to face meetings, listen to other parents Parent network, get yourself out
• Training and advice from SLT	10/250 10/258 15/415 15/424 27/801 40/1205 47/1218 42/1273 45/1378 46/1403 47/1443 53/1632 56/1726 56/1734	Amazing, nodding Incredible, just everything, real moment Told me to refer, felt validated Like God More confident Regular emails, inviting, trained anytime, questions Any questions, no problem Getting support need SLTs name, all ears, said been on training course Would have turned me down Learnt how to be at home, helpful Email, suggestions, print outs Only with SLTs help, game changer Validated everything, confidence

Table O2

Delia's Themes

Table of all Superordinate Themes and Subordinate Themes for PP 2 (Delia)		
Themes **Superordinate theme** Subordinate theme	**Page/Line Numbers**	**Key Words**
1. Onset		
• Nature and nurture	10/261 10/264 30/912	We are bilingual, confusing Born like that, innate anxiety, intrinsic anxiety Different language plays a role, blame, struggling to distinguish, bit confused
2. Impact on the Child, Parent, and Family		
• Impact on the child's independence	14/373 14/388	Do everything for him Cannot express himself, won't be able to do it
• Impact on child's emotional wellbeing	9/212 12/321 31/930	Severe anxiety, threading hair, hat Would like to be like other kids, doesn't enjoy life Pulling hair, chewing nails
• Impact on mother's emotional wellbeing	12/335	Get older, affect friendships

	15/409 15/411 15/418 15/423 26/777 32/963 32/967	Stress, life more difficult, struggle All of his anxieties plus SM, struggle, difficult Stress, anxiety Worried about the future, how he will be as an adult Doesn't change, medication Stressed, bad days Constant worry, notice he is different, disaster scenarios
• Impact on the emotional wellbeing of the whole family unit	16/440 34/1041	Everybody are concerned Everybody, younger sister, infectious, transmits
3. Supportive School		
• School staff are understanding and accommodating	7/165 13/353 16/461 18/524 25/724 25/733	Teachers are brilliant, aware, non-verbal communication Shows one hand for yes, the other for no, writes Take seriously, keep in mind, adjust Try not to push, take it account particularities, One or two more children, school understands Different ways to communicate, wear hat
• Parent and school work in partnership	7/167 16/461 17/476 17/482 19/531 27/797 29/865 29/880	Meetings Several meetings Big meeting, discussing everything, welcomed Discuss how to handle Several meetings, give me a call, my permission Done their part Doing their part Together we make plans
4. Barriers to Supporting the Child		
• Lack of school resources	22/643	Something else happens, busy, tired, forget

• Lack of access to professional support	24/704 24/711	Not possible to happen This is it, don't know, you know more
5. Improvements to Support for the Child		
• Support from a specialist	20/568 24/704 26/779 27/803 34/1040	Paediatric Psychologist, need something more Would like to be seen by a Psychologist Need to see specialist, guide me, don't have the experience of a professional Socialist support Guidance
6. Taking on the Role of an Advocate		
• Mother fighting for support	6/117 17/493 21/596 21/600 21/615 31/940 34/1012	My initiative, suspected Started this Nothing would have been done, everything come from me, started by my initiative Pushed Struggle, push Start it myself, "I", investigation, hired, convince, fight Keep fighting
7. Parent's Coping Strategies		
• Focus on the here and now	33/982	Day by day, whatever comes
• Social networking	30/896 33/989	Give their perspective, SMiRA Facebook Group Stories, other parents, testimonies, adults with SM

Table O3

Vicky's Themes

Table of all Superordinate Themes and Subordinate Themes for PP 3 (Vicky)		
Themes **Superordinate theme** Subordinate theme	**Page/Line Numbers**	**Key Words**
1. Onset		
• Nature and nurture	10/261 10/266 10/271 12/306 12/332	Husband, trouble speaking, genes Her genes, her individuality Nature and nurture Sensitive, clingy Stutter, absolutely petrified
2. Impact on the Child and Parent		
• Impact on the child's emotional wellbeing	14/378 19/536 20/566 20/570	Cuddle key worker, cry, lost Sensitive, sad, mental health, depression, isolation Hides Scared, sad
• Impact on the child's social interaction and relationships	6/120 16/446 18/510 18/512 19/529 19/547	Grandmother, an hour or two to warm up Socialisation, grandparents, smoother her Friendships, doesn't communicate Doesn't have the ability to say "hello" Next door neighbour, stands there, invisible Can't talk to them, struggles waving

• Impact on the child's education	4/73 17/475 17/482 17/490 27/810 30/878 30/897	Total lack of participation, library rhyme time, turn away Phonics classes, sat sideways Singing and dancing, struggle, get behind Group learning, issues in the future French class, never participate, stay on the outside Communicate with the teacher, after school club Learn, freak her out
3. Supportive Nursery		
• Dedicated key worker	6/139 15/426 16/440 22/606 28/832 30/907	Huge amounts of effort Amazing, develop relationship, effort Would freak Can tell her key worker Keeps an eye out Build up that trust and relationship, feel comfortable
• Accommodating nursery staff	24/702 24/713 25/726 26/771	Amazing, really good, doing everything they can Open, supportive Brilliant Break out into her room, helped settle her
4. Barriers to Supporting the Child		
• Parent left in the dark in terms of available support	29/858 31/933 41/1261	Don't really know, anything else available? Don't really know, curious Educational Psychologist, no idea
• Lack of understanding	4/63 9/215 13/363 14/383 14/399	Grow out of it, don't worry Books, grandparents don't understand Some people are just sensitive They will be fine, didn't help It's fine, just go

	36/1100	Don't really get it, put it down to being shy
5. Improvements to Support for the Child and Parent		
• Clearer guidance and support	34/1000 35/1062 36/1104 37/1127 38/1147	Plan, structure, goals, care plan Pathway, strategies at each stage What they can do, where they can go Specialist, interest, knowledge, special interest Can't expect everyone, make it known
6. Taking on the Role of an Advocate		
• Mother fighting for support	7/172 21/614 29/854 36/1078	Knew there was an issue Looked up, Speech and Language Therapist, advice Speak to SENCo, see what's available Involvement from Speech and Language Therapist
7. What has Helped the Parent		
• Acceptance and preparation	39/1187	Knowing, depression, bullying being aware, do the best

Table O4

Laura's Themes

Table of all Superordinate Themes and Subordinate Themes for PP 4 (Laura)		
Themes	**Page/Line Numbers**	**Key Words**

Superordinate theme Subordinate theme		
1. Onset		
• Uncertainty about the cause	17/483 18/506	Don't know, best pregnancy, no upheaval, calm I'm really confident and outgoing
2. Impact on the Child and Parent		
• Impact on the child's emotional wellbeing	7/169 20/563 21/622 24/702 24/717 26/770 26/775 48/1271 57/1754	Birthday parties, stand by my side Everyday life, hinders, everything 1000 percent Worries Really worries, little panicker Emotional health, affected so much Hurt her, deeply, no ability to brush off Confidence, silly, inadequate Not happy
• Impact on the child's social experience	5/100 5/109 6/135 7/169 13/357 15/409 20/580 20/591 21/610 21/616 26/762 47/1437	Never spoken to family Nursery, other children Other children, think she's being rude Birthday parties, won't go and play Stubborn, head down, tuck herself inwards Incident, pony tail, ripped it out Side lines, wants a best friend, wants to play Watch in Doesn't talk or play with any of them Children know she won't talk and don't bother Bullied Sits back and watches

• Impact on the child's education	10/261 10/269 15/434 16/438 22/644 22/654 26/755 38/1142 38/1148 38/1165 45/1384 45/1388 47/1449 48/1466	Doesn't know how to read, write Will not ask for help, just sit there School plays, won't join in Not under any circumstances Don't know what's going in Behind, never been on target Doesn't learn Won't let go of hand Clings onto me, tears down face, never wants to let go Attached, usher in Doesn't like it Doesn't like it School play, couldn't go on stage Sports day, hard
• Impact on the child's physical wellbeing	7/148 7/155 9/230 9/240 23/677 24/724 53/1620	Incident, burnt fingers, holding pain in Won't accept food, rather sit there starving Doctors, bumped head, just sat there Hurt her Won't tell me if hurt herself Stomach aches New shoes, cardboard
• Impact on the mother's emotional wellbeing	5/107 25/746 27/799 28/818 28/825 30/890 30/893 42/1280 52/1586 52/1607 53/1622	Really tough Bad parent, crying, horrendous, horrible Sad, crap, rubbish Mum Anxious, affects child, lie to my child Feel rubbish all day Cautious, who I have in my home Quit jobs, started college, couldn't cope Frustrating, depressed, abusing daughter Overpowering, setting unrealistic expectations Confused, really tough Frustrating

	53/1637 53/1641 54/1651 54/1665 55/1691 57/1752	Don't ever get any time, safety blanket, very attached So much love, overly given it, setting her up for failure Never really happy, crazy person, worry Suicidal, gets to you, happiness of child Sad, suffering Difficult emotionally, emotionally hard
3. Barriers to Supporting the Child		
• Lack of resources	11/298 16/447 32/963 34/1011 36/1093 43/1323 55/1687 56/1717	Not a lot about SM, difficult to get information Only so much a teacher can do Not a lot there Hands are tied Teacher can't put any support in EP not available No money, not enough money Can't find advice anywhere
• Lack of collaboration	34/1023 35/1071 37/1115 39/1210 39/1214 43/1323 43/1331 43/1337	Haven't told me Said want a meeting every term Not involved Not mentioned Haven't mentioned Phone call, EP, never heard that Phone call, EP, wasn't aware Didn't tell me
• Lack of identification	8/184 8/188 56/1726	Never been proactive, doesn't cause any fuss Forgotten child, she was ok Told me she's fine, never has been fine
• Lack of adaptability and intervention	11/285 15/426 32/972 34/1010	Haven't given any real help, could have done more Only thing, smiley face system SLTs recommendation, unrealistic SLT recommendation, impossible ask

	44/1042 35/1051 40/1202 41/1235 41/1238 43/1312 45/1375 47/1449 48/1466 49/1520	Just smiley face system Nothing SLT recommended, nobody else Nothing Nothing, very poor support EP make them put things into place Teacher will still ask questions School play, expected to go on stage Sports day, got to participate Looking back, put in support years ago
4. Improvements to Support for Child and Parent		
• One-to one-support	58/1794 58/1803	One-to-one, there for them, emotionally rely on Always there for them
• SM parent support group	51/1551 51/1562	SM group, meetings for children and parents Beneficial, positive thing
5. Taking on the Role of an Advocate		
• Mother fighting for understanding and support	11/280 11/303 26/764 27/807 31/935 32/954 32/958 35/1073 36/1085 38/1160 39/1177 39/1194	Explained to school, cannot go through this, need daughter to be appropriately supported Proactive in getting help, what they deserve Bullying, no longer coming in Over the top Wanted a plan, needed to do something Googled her Trawled the internet Meeting every term Work with them Take something in everyday, animal My idea A thousand percent

	55/1707 56/1736 57/1764	Will go and seek other support Got personalities, have feelings, want to be known Act crazy, forceful
6. What has Helped the Parent		
• Distraction	54/1654	Tidy up, forget

Table O5

Charlotte's Themes

Table of all Superordinate Themes and Subordinate Themes for PP 5 Charlotte)		
Themes **Superordinate theme** Subordinate theme	**Page/Line Numbers**	**Key Words**
1. Onset		
• Family history of mental health difficulties	12/310 13/339	Pass down, generations, my side of the family Genetic thing, more predisposed
2. Impact on the Child and Parent		
• Impact on the child's emotional wellbeing	13/367	Confidence issues, holds him back
• Impact on the mother's emotional wellbeing	19/559 13/363 20/571	Worried Progresses through life, school performance, job End of school year, fret

3. What has Helped the Child		
• School staff are accommodating	6/123 7/159 15/424 15/429 26/759 39/1182	Cards for toilet Accommodating Reads with key worker Reads to key worker, assess that way Took on board, twin and best friend in class Transition, booklet, photos, information
• Dedicated key worker	6/117 9/238 17/474 17/495 20/575 21/609 22/641 24/700 25/734 27/800 35/1066 39/1186	Fight, continuity Key worker, involved early on, things took off Supportive, spend time, make sure ok, entire day Once or twice a week, spend time, games, reading Doing everything she can to fight Come from key worker, pushing Taken on, project Slide in other teachers Raise awareness Left to own devices, key worker, huge difference Talks to her, trusts her, fantastic Home visits
• Mother and staff working together	5/92 9/212 9/240 16/434 22/653 23/672 26/782 29/875 39/1186	Slide her in, she and I worked on Nursery, Dictaphone, work through it Went on the course together Record, reading, send to the teacher Contact with key worker and teachers Sliding in, every Monday, working with key worker Informed, chat, keep me up to date, contact book Work together, overcome Home visits

4. Barriers to Supporting the Child		
• Lack of recognition	4/67 7/170	Nothing mentioned, didn't pick up, twin outspoken Nursery, comment in passing
• Lack of understanding	4/77 9/235 32/944 33/986 36/1099 37/1107 37/1123 41/1235 42/1264	Not on radar, didn't know what it was, no clue Didn't know anything Nobody understood, nobody got why Schools, not gonna know, steep learning curve Don't understand, putting on the spot, grandparents Worst thing, punish for not speaking Different generation Little awareness, more formally recognised Haven't got a clue
• Lack of access to support services	21/608 27/811 28/820 29/868 29/875	Not much, not investing funding Stopped investing Speech and language assistant, funding stopped Diagnosed, over to you Wasn't much else could do
5. What has Helped the Parent		
• SM training course	24/696 30/886 34/1022 34/1033 35/1043	Sliding in, course, material Training, fantastic Better, fantastic, slotted into place, everything Path forward Sliding in technique, taught, videos, helpful
• Acceptance of SM	18/508 20/558 40/1210	Learnt to live with it More relaxed, work through it Try not to worry
• Social networking	30/888	Helpful, reassuring, other parents, same situation

	30/898 30/906 31/914 35/1058	Facebook groups Looked up, joined, read things, posts Recommendations, books Talk to other people, same situation

Table O6

Steph's Themes

Table of all Superordinate Themes and Subordinate Themes for PP 6 (Steph)		
Themes **Superordinate theme** Subordinate theme	**Page/Line Numbers**	**Key Words**
1. Onset		
• Genetics contributed to onset	18/515 19/542	Jury's out, genetic predisposition, young age Dad's side, every member of family
2. Impact on the Child, Parent, and Family		
• Impact on the child's emotional wellbeing	9/222 24/705 29/866 30/886 54/1649 57/1744 57/1756	Worrying her, meltdowns, all through the night Lacks confidence Unhappy, depressed, September Unhappy, furious, meltdowns Sleeping, takes hours, hearts beating too quickly Holding it together, exhausted, anxious tension Angry, angry crying, cross, hit, kick

• Impact on the child's social experience	6/127 6/141 8/183 8/188 9/209 10/249 20/573 27/802 44/1334	Wouldn't initiate conversation Staff, answer yes or no, nod, one word hard work Bullied Reception, older girls, lunch time, hated it Stand on a stage, timer, speak for five minutes, state Tapped into insecurities Delayed in making friendships Stand on her own Horrible girls, slowed down, delayed things
• Impact on the child's education	14/392 20/577 21/607 28/849 29/866 30/891 33/982 35/1046	SEN register, hardworking when anxious Nervous, frozen, freezes Doesn't read, can't assess Below Dreading going back to school Dressed for school, undressing herself "Don't wanna go to school", upset at drop-off "I'm not going", pull her hands off
• Impact on the child's expression of physical needs	7/153 24/718 25/740	Pebble, loo, too much, painful Freeze up with the GP Wetting herself
• Impact on the mother's emotional wellbeing	16/454 29/871 30/901 31/921 31/928 32/945 41/1254 57/1772 58/1783	Frustrated, dragged little one in there, argh Hard, awful, hideous, hard standing at school gates Breakdown, didn't know what to do, panic attack Took a month off work Anti-depressants, CBT Anxious, really hard Frustrating, only chance Couldn't handle, shout, exasperated Dark times

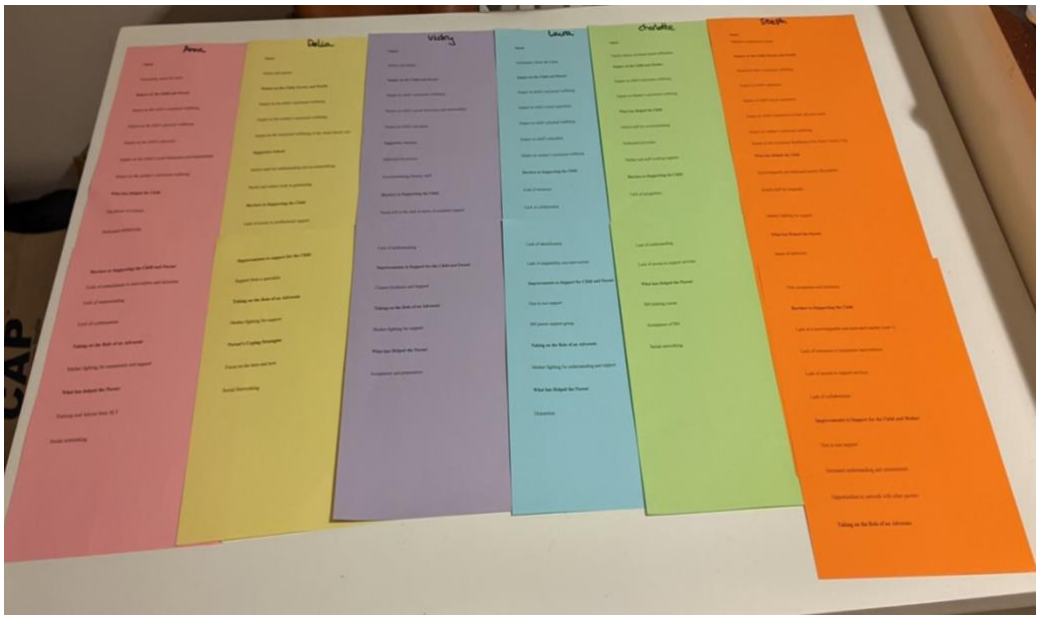
• Impact on the emotional wellbeing of the entire family unit	33/977 47/1449 51/1569 57/1750	Sister, doing to her, unhappiness Joining another family, awful, disaster Tough on relationship, takes its toll Impact on families
3. What has Helped the Child		
• Knowledgeable and dedicated teacher (Reception)	11/287 11/296 12/306 12/311 14/388 14/397	Hinted, pick it up, amazing Recommended books and manual Incredible, wish could have her forever Experienced, amazing Already knew, already implementing things Listened to teacher, went with what she said
• School staff are adaptable	26/756 36/1094 38/1137 39/1167 39/1199	School dinners, TA, eat in a small room together Different playground, lunch time with smaller number of children Won't put on the spot, careful Careful, sitting next to, chosen carefully Playground, choice
• Peer acceptance and inclusion	23/679 24/697 27/807 28/820 28/833 61/1880	Kids in her class, lovely, no expectation She's just Hazel, take her as she is Friend, pretending to be cats Friendly, like school now Massive difference They don't mind, feels included
4. Barriers to Supporting the Child		
• Lack of a knowledgeable and dedicated teacher (year one)	15/413 16/438 16/451 42/1284	Didn't do any of that, couldn't get hold of him Sliding in, leaving the classroom, not coming back Not come back, frustrated Get it enough

	43/1311 56/1730	Rubbish, not engaging, didn't make a difference Real shame, not made effort
• Lack of collaboration	37/1108 37/1123 41/1263	No regular meetings Not much opportunity Don't really invite us in
• Lack of resources to implement interventions	17/462 17/478 17/489 41/1254 44/1350	Too busy, pull the teacher out, protected time Tricky, shifts, little availability, difficult to achieve Once a week, work Stretched financially Can't do it on our own, not enough hours
• Lack of access to support services	12/321 13/338 13/356 14/369 41/1242 44/1346	Not severe enough, parenting support, school nurse Primary Children's Mental Health, turned down Speech and Language don't deal with it Lost Haven't taken her up Doesn't seem many services interested
5. Improvements to Support for Child and Mother		
• One-to-one support	45/1364	Massive dream, proper sliding in, same person
• Increased understanding and commitment	38/1154 42/1284 45/1377 50/1550	Haven't taken the time to find out enough Protected time Need a plan, stick to it, times ticking on Learn more, emphasis on parents, meet us half way
• Opportunities to network with other parents	48/1487 49/1494 49/1517 50/1534	Meet up with someone going through it, coffee, chat Some go "I know", friends, no one's living it SEN support group, can't join in Talk to someone at the same point

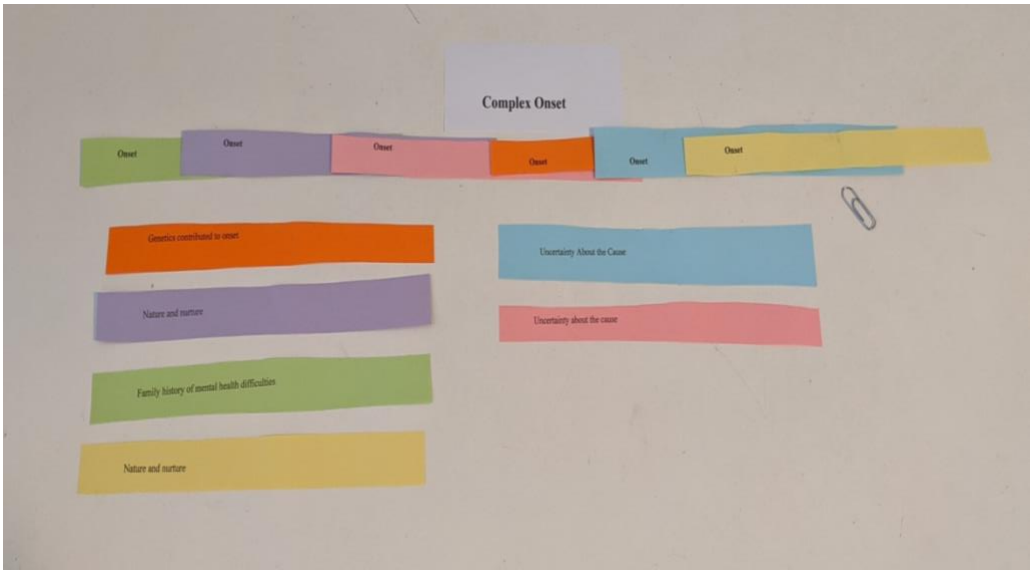
6. Taking on the Role of an Advocate		
• Mother fighting for support	8/191 9/231 13/314 14/369 14/395 15/418 35/1063 56/1375 56/1718	Bullying, spoke to the SENCo, handled not as well Took me going in, annoyed, kick up the bum Asked for referral to school nurse Paid, privately SENCo, pushed Reading up, references, tried to get into contact SENCo, have to be pushy Exhausting, pushing, need to say that need a plan Pushy, just keep on, no one else is going to do it
7. What has Helped the Parent		
• Sense of optimism	53/1614 53/1631	Can be confident, you've got this, you'll get there Got it in you, happen with time

Appendix P: The Process of Clustering Common Themes Across Participants

All Superordinate and Subordinate Themes Laid Out for all Participants



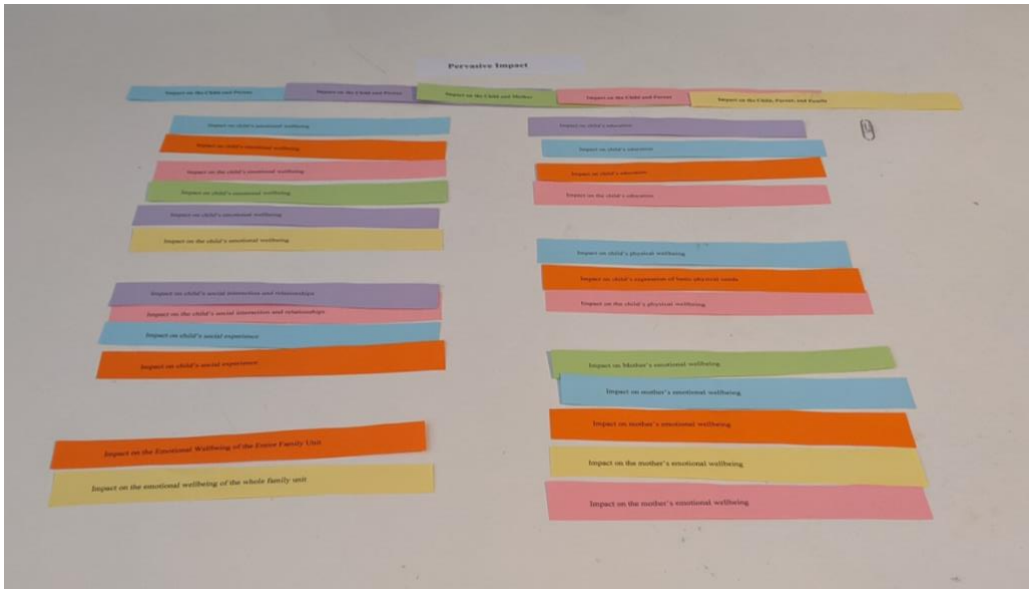
Formation of the Superordinate Theme 'Complex Onset'



Typed out for clarity:

- Genetics contributed to onset
- Nature and nurture
- Family history of mental health difficulties
- Nature and nurture
- Uncertainty about the cause
- Uncertainty about the cause

Formation of the Superordinate Theme 'Pervasive Impact'



Typed out for clarity:

- Impact on the child's emotional wellbeing
- Impact on the child's emotional wellbeing
- Impact on the child's emotional wellbeing
- Impact on the child's emotional wellbeing
- Impact on the child's emotional wellbeing
- Impact on the child's emotional wellbeing

- Impact on the child's social interaction and relationships
- Impact on the child's social interaction and relationships
- Impact on the child's social experience
- Impact on the child's social experience

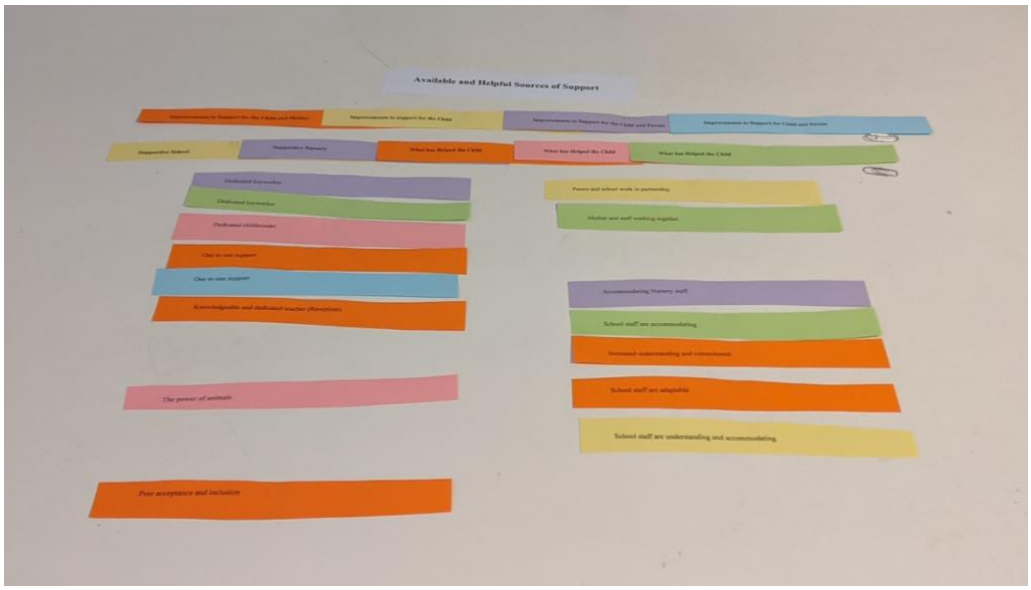
- Impact on the emotional wellbeing of the entire family unit
- Impact on the emotional wellbeing of the whole family unit

- Impact on child's education
- Impact on child's education
- Impact on child's education
- Impact on child's education

- Impact on child's physical wellbeing
- Impact on child's expression of basic physical needs
- Impact on child's physical wellbeing

- Impact on mother's emotional wellbeing
- Impact on mother's emotional wellbeing
- Impact on mother's emotional wellbeing
- Impact on the mother's emotional wellbeing
- Impact on the mother's emotional wellbeing

Formation of the Superordinate Theme 'Available and Helpful Sources of Support'



Typed out for clarity:

- Dedicated keyworker
- Dedicated keyworker
- Dedicated childminder
- One to one support
- One to one support
- Knowledgeable and dedicated teacher (Reception)

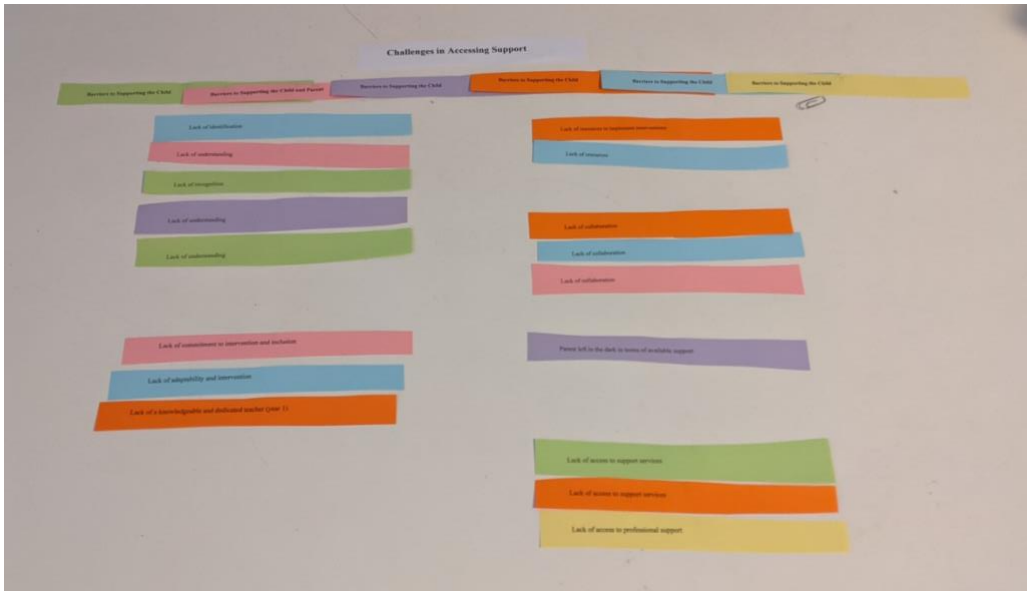
- The power of animals

- Peer acceptance and inclusion

- Parent and school work in partnership
- Mother and staff working together

- Accommodating nursery staff
- School staff are accommodating
- Increased understanding and commitment
- School staff are adaptable
- School staff are understanding and accommodating

Formation of the Superordinate Theme 'Challenges in Accessing Support'



Typed out for clarity:

- Lack of identification
- Lack of understanding
- Lack of recognition
- Lack of understanding
- Lack of understanding

- Lack of commitment to intervention and inclusion
- Lack of adaptability and intervention
- Lack of a knowledgeable and dedicated teacher (year 1)

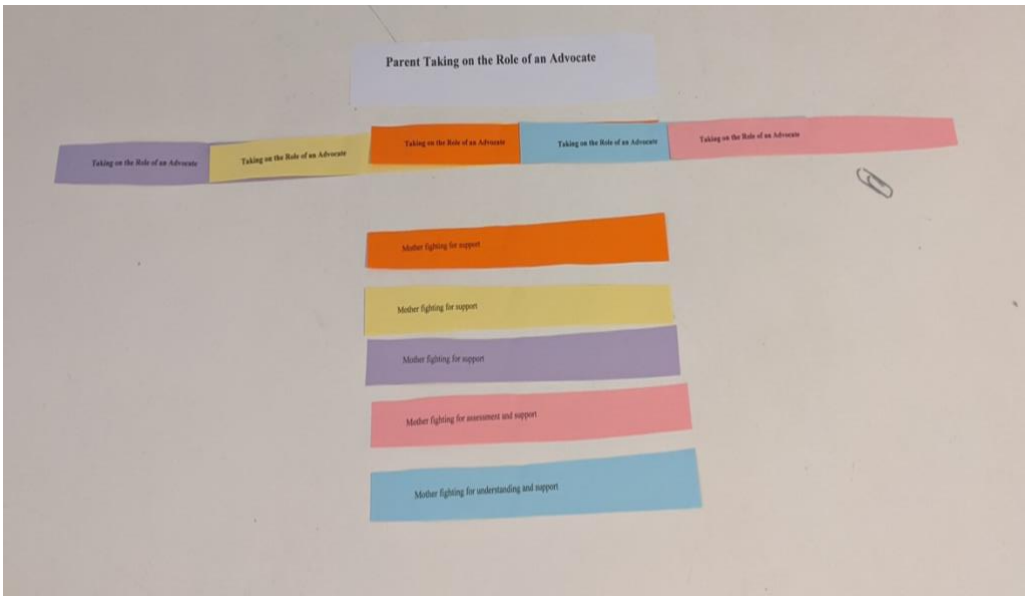
- Lack of resources to implement interventions
- Lack of resources

- Lack of collaboration
- Lack of collaboration
- Lack of collaboration

- Parent left in the dark in terms of available support

- Lack of access to support services
- Lack of access to support services
- Lack of access to professional support

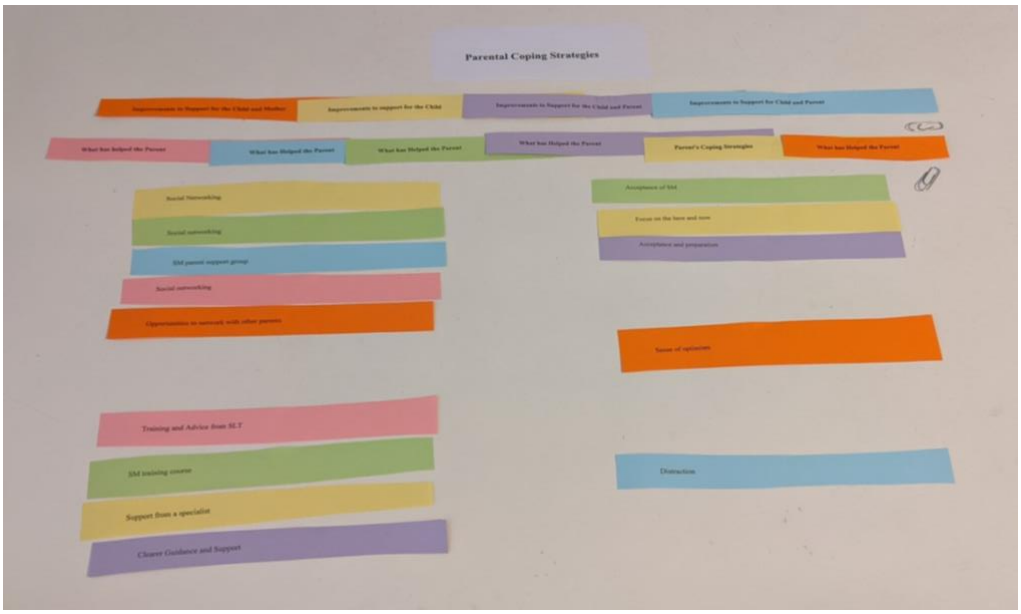
Formation of the Superordinate Theme 'Parent Taking on the Role of an Advocate'



Typed out for clarity:

- Mother fighting for support
- Mother fighting for support
- Mother fighting for support
- Mother fighting for assessment and support
- Mother fighting for understanding and support

Formation of the Superordinate Theme 'Parental Coping Strategies'



Typed out for clarity:

- Social networking
- Social networking
- SM parent support group
- Social networking
- Opportunities to network with other parents

- Training and advice from SLT
- SM training course
- Support from a specialist
- Clearer guidance and support

- Acceptance of SM
- Focus on the here and now
- Acceptance and preparation
- Sense of optimism

- Distraction